



Best Wishes for Christmas to all our readers!



Picture by Colin Mearns.

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Brave Caleb's Fight-back.

Cate Devine. The Herald.

A visit to the optician was the start of a journey seven-year-old Caleb Duffy could never have imagined. He had been suffering severe headaches for months that were so bad he was being sick. The family GP said it was a virus and prescribed antibiotics. But the symptoms kept returning. So mother Stephanie took him to an optician in Shotts, Lanarkshire, to see if he needed glasses. And it was then his life changed forever. He was immediately referred to hospital and, within days, was diagnosed with a brain tumour sitting perilously close to his pituitary gland... (Caleb's story continues overleaf.)

The Duffy family contacted Brain Tumour Action for advice and now The Herald has most generously decided to support us from the sales of their 2012 Charity Calendar.

Profits from this beautiful calendar, which showcases the best of The Herald readers' photographs, will go to Brain Tumour Action. The calendar is on sale now for £7.50 (inc p&p) but only until December 16th. Order on-line at

<http://login.heraldscotland.com/heraldcalendar/order.cgi>

or by phone (0141 302 7300) or by visiting The Herald offices at 200 Renfield Stret, Glasgow G2 3QB.

For The Herald to support us like this allows us to help more people become aware of the serious problems facing children diagnosed with a brain tumour and to contribute to improving outcomes. A desperate lack of funding for research, delays in diagnosis, variable prognoses and gruelling treatments are some of the challenges – but see the promising new developments in minimising radiation damage on page 5!

Brave Caleb's Fight-back (contd.)

Caleb underwent a nine-hour operation at the Southern General Hospital in Glasgow to have his tumour removed. It was a high-risk procedure because of the tumour's location and the neurosurgeons only went in as far as they safely could.

When he was brought out of sedation Caleb's vision and movement were miraculously undamaged. But doctors had only been able to remove 75% of the tumour. He needed radiotherapy to shrink the remaining 25%.

However, the NHS only has access to Photon therapy which is risky for children at a certain age as it can cause collateral damage to the rest of the undeveloped brain. Proton therapy is much more precise – and much more expensive.

But the unexpected offer of a trip to the pioneering Proton Therapy Institute at the University of Florida, funded by the NHS, meant Caleb received the best possible treatment.

"The decision to go to Florida was massive for the whole family," said his father Sean, group advertising director at The Herald & Times.

Meanwhile, with his mother by his side, Caleb endured daily hour-long doses of treatment for 35 days except at weekends. He had a special head mask made out of mesh to enable his head to stay completely still. Not once did he opt for sedation or express fear or anxiety.

"I could not do what Caleb has done," said his mother. "We are in awe of him. He is our hero." Stephanie said: "We are keen to help Brain Tumour Action who raise awareness of brain tumours and the need for early diagnosis, especially in children."

The Perfect Christmas Gift!

The Herald 2012 CALENDAR



in aid of

Brain Tumour Action



Such has been the continuing popularity of The Herald Picture of the Day and such has been the quality of photographs submitted this year, that we have decided once again to publish the best images from the past year in a 2012 Herald calendar for everyone to enjoy. The calendar is 320mm x 470mm and contains 12 double page spreads with memo block dates. All profit from sales of the calendar will go to Brain Tumour Action.

HERALD 2012 CALENDAR

The Herald calendar costs £7.50, including VAT with £2.60 from every sale going direct to Brain Tumour Action. The remainder covers costs only.

To order your calendar, fill in the coupon below, and send with your cheque or postal order, made out to Herald & Times Ltd, to The Herald Charity Calendar Offer, Marketing Dept., 200 Renfield Street, Glasgow G2 3QB. Offer ends Friday December 16, 2011. Offer subject to availability.

TITLE:.....
NAME:.....
ADDRESS:.....
POSTCODE:.....
TELEPHONE NUMBER:.....
EMAIL:.....

I require calendars at £7.50 each (UK postage only).

Total cost £..... (cheque/postal order enclosed).

Herald & Times Group may like to send you details of other goods and services that may be of interest to you.

If you do not wish to receive further information from Herald & Times please tick this box

The Herald charity calendar can also be purchased online at <http://www.heraldscotland.com/heraldcalendar> or by visiting The Herald Reception, 200 Renfield Street, Glasgow G2 3QB at a cost of £6 (excluding p&p costs)

The Herald

A DATE FOR YOUR NEW DIARY: The Annual General Meeting.

The next Annual General Meeting of Brain Tumour Action will take place on Tuesday, January 17th, 2012 at 6pm. It will be held in the offices of French Duncan, 56, Palmerston Place, Edinburgh EH12 5AY.

New committee members are actively being sought so if you feel you would like to get involved in our charity in whatever capacity please don't hold back. Everyone is most welcome to come along.

To receive a nomination form please email: administrator@braintumouraction.org.uk or telephone 0131 466 3116.

Celebrating His Half-Century

Nearly twelve years ago Anthony was diagnosed with a low grade glioma. Although low grade, we were warned that the long term survival was uncertain.

In 2006 Anthony experienced progression of his tumour and was given further, stereotactic radiotherapy at the Western General Hospital in Edinburgh. I had thought that he wouldn't live to see his fiftieth birthday but as you can see from the photo Anthony has reached this milestone. We celebrated with a big party beforehand and then a meal out on the actual day, the 24th October, 2011.

Anthony is now a long term survivor of a brain tumour and this is great. However we mustn't forget the

problems he, and others like him, have to live with. He no longer works and hasn't done so since 2002. He has short term memory problems and he finds doing complex tasks impossible (e.g. gardening or DIY).

When we read about the survival success stories we must always remember to look at the quality of life and must try to ensure that treatments don't cause too much damage to the brain.

We have had many ups and downs over the last twelve years yet despite all these problems the tumour hasn't destroyed his sense of humour and Anthony is already looking forward to the next party!

Julie Read.

**Congratulations,
Anthony**



Thank You for Your Generous Donations.



Sophie in Action!

Thank you so much to the generous organisations and individuals who have recently donated to Brain Tumour Action. The money you have raised will help to improve the lives of people affected by a brain tumour. We rely wholly on contributions such as yours to let us continue this valuable work. All of us work voluntarily at Brain Tumour Action, seeking the day when this disease will finally be eradicated.

- Heart of Midlothian Supporters Club, Jambos Kickback
- Beauty Therapy Department, Motherwell College
- Waitrose Morningside, Multithon Trust
- Institute of Pharmacy and Biomedical Sciences, University of Strathclyde
- Ross Mackenzie, Moira Wylie, E Savage
- J Masters, Fiona Carmichael
- Judith Moggach, G W Buchanan
- Carol McGhee, Annmarie Butlin
- Doreen Marion Hutton (Estate)
- Erica Hambly, Phil Archer, Janet Ringrow
- Matthew Herbert, (See page 8) Sophie Gunner

Sophie Gunner has booked with Charity Challenge to participate in the Great Wall Discovery in China on 12/05/2012, in aid of Brain Tumour Action. Well done, Sophie - we hope you have a brilliant time!

What we have been doing, thanks to your generosity.

Brain Tumour Action has been able, thanks to your generous support, to make two significant donations this year.

The first is a major contribution to the Edinburgh Centre for Neuro-Oncology which has launched a £250,000 Appeal to raise funds for the purchase of its first intra-operative ultrasound system to assist in making brain surgery safer.

Intra-operative ultrasound means the use of ultrasound imaging during brain surgery. More and more neurosurgeons are seeing the benefits of this technology and significant advances have been made with its more widespread use in recent years.

At the start of any operation the surgeon has a clear idea of the task at hand but sometimes the circumstances change during surgery.

Soft tissue can move around. Working inside someone's brain is particularly delicate and potentially risky. This makes intra-operative ultrasound imaging a useful tool for making the safest decisions during the actual procedure. Often new information can be gleaned with an intra-operative scan which helps the surgeon successfully complete the surgery based on the most current and accurate information available.

We are delighted to have been able to support this important Appeal.

Funding Research with our Partners

We have also provided funds to support research at the University of Portsmouth as a partner charity of Brain Tumour Research. The Cellular and Molecular Neuro-Oncology Research Group, which was established at Portsmouth following the relocation of Professor Geoff Pilkington from King's College London in 2003, dedicates its research to focussing on the cellular and molecular mechanisms of brain tumour development and progression.

Although the survival times of brain tumour sufferers remains poor, research into this area reportedly receives less than 0.7% of government funding, a disproportionately small sum given that brain tumours kill more children and adults under the age of forty than any other cancer.

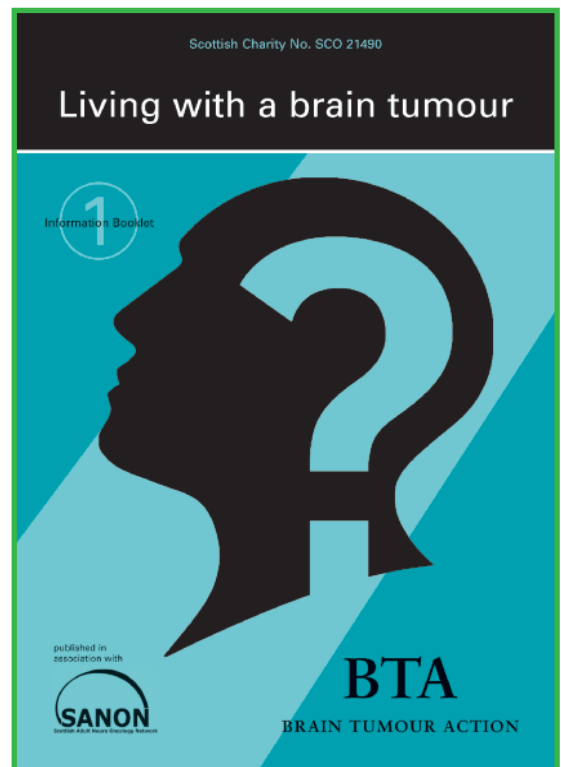
Aromatherapy

We have continued to fund aromatherapy sessions for patients at two centres in Scotland, a service we have been offering for over twelve years. We hope to be able to provide the same service at another centre next year. Patients find these one-to-one sessions both energising and soothing, particularly during radiotherapy treatment. Please contact us for further details of times and places.

Now in its third edition

Our widely-distributed booklet, the twenty-four page 'Living with a Brain Tumour' has just been revised and reissued. 'Living with a Brain Tumour', first printed seventeen years ago, is the publication people most often request; this is now its third edition. Among other topics discussed are the impact of diagnosis, physical and emotional responses, tumour types as well as symptoms and treatments, coping strategies and much more.

Our next booklet to be reissued will be Radiotherapy for Brain Tumours which is due to be printed early in 2012. That will be followed by Brain Tumours and Epilepsy. All these booklets and our eight other information leaflets are available on the website as well as in printed paper form.



Working to reduce Radiation Damage - EXCITING NEW RESEARCH FINDINGS.

Individuals who receive radiation therapy (RT) for the treatment of primary and metastatic brain tumours can develop cognitive deficits that include decreased attention and concentration, as well as poor short-term memory, when assessed six months after treatment. The severity of these deficits worsens with time and can negatively impact the patient's quality of life (QOL).

Ongoing studies in the laboratory of Mike Robbins, PhD, Department of Radiation Oncology, Wake Forest School of Medicine, North Carolina, suggest that these potentially devastating side-effects may be preventable. Dr. Robbins leads the Radiation-induced Brain Injury and Treatment Group, a multidisciplinary team of scientists and clinicians who strive to improve the QOL of brain tumour patients.

Utilizing a novel, preclinical model in which adult male rats received a four week course of fractionated whole-brain irradiation, the Robbins lab tested the hypothesis that administering drugs with anti-inflammatory properties would be able to prevent or reduce the severity of radiation-induced, cognitive impairment. To ensure that these laboratory findings could be rapidly

translated to the clinic, the Robbins lab chose drugs commonly prescribed for the treatment of other disorders that also appeared to have anti-inflammatory effects.

Two main classes of drugs were used. The first were those that activate a family of receptors called peroxisomal proliferator-activated receptors, or PPARs. The name of the drug we studied is pioglitazone which specifically activates PPAR and which has been used clinically to treat Type Two diabetes for several years.

Administering pioglitazone prior to, during, and for up to one year after whole brain irradiation can prevent radiation-induced cognitive damage assessed one year after irradiation. Additional studies demonstrated that the drug is also effective when given prior to, during, and for only five weeks after irradiation. Based on these exciting findings, we have initiated a Phase I clinical trial to assess the maximum dose of pioglitazone that we can administer to brain cancer patients receiving RT.

The second class of drugs we studied was two types of anti-hypertensive drug used to treat high blood pressure. These are angiotensin-converting enzyme (ACE) inhibitors and

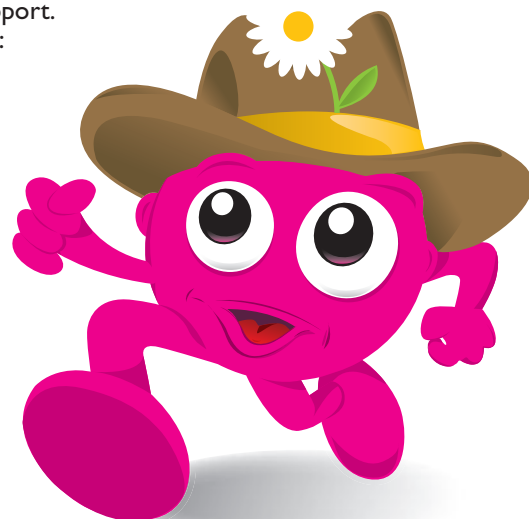
angiotensin receptor blockers (ARBs). ACE inhibitors have been used for over thirty years and ARBs for nearly twenty. Both types of drug are very well tolerated with a low risk of side-effects. Administering either ramipril, an ACE inhibitor, or l-158,809, an ARB, can prevent radiation-induced cognitive impairment in our rat model. Since ramipril has been shown to be well tolerated, we are in the process of setting up a Phase II trial to determine if the drug will prevent or reduce the severity of radiation-induced cognitive impairment in brain cancer patients.

It is important to ensure that the protective effect of these drugs on normal brain tissue is not seen in brain tumour cells. A promising feature of both classes of drugs is that they do not protect the tumour cells against radiation. If anything, they inhibit tumour growth by directly killing the tumour cells or by reducing their ability to recruit blood vessels to support their growth. Although there is much more work to be done, we believe that we are on the threshold of establishing novel, interventional therapies that will not only improve brain cancer patients' survival following RT, but also improve their QOL.

Mike Robbins PhD.

'Wear a Hat for Brain Tumours' day! Friday March 30th, 2012.

1. Choose someone as your Wear a Hat for Brain Tumours team leader to rally support. Call us on 0131 466 3116 or email for posters, leaflets, sponsorship forms, etc. to: administrator@braintumouraction.org.uk
Tell us how we can best help you with your plans.
2. Decide what time your event will happen, get approval if necessary and start advertising. Send out invitations and spread the word about brain tumours to everyone you know, asking people to wear a hat and donate a pound or two.
3. Most important: have fun on the day – perhaps you could have a small prize for the silliest hat.
4. Count the money and send it as a cheque made payable to:
Brain Tumour Action at: Brain Tumour Action, 25 Ann Street, Edinburgh EH4 1PL.
5. If you have any great photos of the day and you're happy for us to share them on our website, please send them too.
Good Luck and Thank You for Making a Difference!



PLEASE HELP SUPPORT & FUND BRAIN TUMOUR RESEARCH ACROSS THE UK

Putting on a brave face?

We try to be here for people in their darkest times, both through our telephone helpline and online. This extract is taken from an email written in reply to someone who was finding it extremely difficult to keep going. Names and identifying details have been omitted.

Your email touches on some of the deepest issues about coping, and not coping, with this terrifying illness. To watch your brave sister struggling on with each gruelling treatment in the knowledge that she may not recover is one of the hardest things you will probably have to live through in your lifetime. It's what some of those who have been in your position describe as feeling like a roller coaster: up and down, up and down, but no getting off the ride.

Personally I believe in not allowing myself to think too far beyond today - which is easy enough to write, much harder to do. If your sister is better tomorrow and you can enjoy each other's company then go for it! That will have been a good day, a day you'll both treasure. But at the same time don't expect her necessarily to be that well the day after. She may be or she may not. We can drive ourselves to despair and back asking the great

"what ifs?" Or we can decide not to ask but to grab each drop of happiness we have now and only later on, to reflect on what it all meant.

Putting on a brave face is what we all instinctively try to do to protect our loved ones and spare them the pain of seeing us suffer but it's a false front since everyone still suffers.

Paradoxically, your best gift to your sister may be if you can both face the fear together. She may actually want to talk about the fact that she could die but feel unable to burden anyone in her immediate family. She may be feeling very lonely, very scared. You can show her that you're always there for her to talk to, always concerned to know how she's feeling, that you're on this journey with her every step of the way and this may free her to unburden her deepest fears to you.

Maybe that sounds quite scary - but if she does so it will ease the pain both

for her and you. We can all go on being falsely bright and cheerful which deceives nobody or we can show how scared and sad we really feel, hold each other and say "yes this is awful, yes I'm terrified you/I may die from the disease and yes we can also share the good times and the terrible, frightening times together."

In fact talking openly about our worst fears often makes them more manageable, less intolerable, and gives us new strength to carry on with the challenges we're facing.

But there will always be days when you just want to curl up and cry, as you say, and that is okay too. It's the process of anticipatory grieving, grieving for what you fear may happen, it is absolutely 'normal', whatever that word means. It is another coping mechanism and it, too, will pass.

Lynne Barty.

Supporting each other

The Edinburgh Support Group meets on the first Tuesday of the month at 7pm. in the welcoming atmosphere of the Maggie's Centre at the Western General Hospital. Newcomers are always welcome, as are their friends and family.



The Group provides a valuable opportunity for patients and carers to give and gain support from each other and to find answers to some of their questions. At a recent session the Government's changes to disability allowances, including blue badge entitlement were clarified. This has been causing considerable anxiety.

However the Support Group also gives everyone the chance to relax, socialise and have a good blether, as you can see from this photograph.

Working with our Partner Charities.

BTUK CONFERENCE.

In September, 2011 Brain Tumour UK held its two-day patient and carer conference in Glasgow for the first time.

There were several speakers who covered a wide range of topics from cellular biology to depression in brain tumour patients so there was something of interest for everyone.

On the first afternoon there were some small groups which dealt with benefits, relaxation and carers.

I was asked to speak at the conference as a carer of someone with a brain tumour. Prior to this I had attended the group session for carers and it was quite moving to hear other people's stories of the difficulties they had dealing with problems their loved ones were experiencing. I gave my own talk just before a patient with a brain tumour who shared her insights into living with this illness.



Charity representatives at the Brain Tumour Research Conference, Birmingham.

I spoke of the journey we had been through over the last twelve years and the ups and downs of the re-growth and transformation of part of the tumour.

I was asked a lot of questions about diagnosis and how it could be improved as I had told the conference I was a GP. There was a lot of constructive discussion afterwards and I think the talk was well received.

Conferences like these are always well attended as they attract people searching for answers as well as health professionals who want to find out more about brain tumours and the impact they have.

A Carer

BTR WORKSHOP.

On the evening of 30th October representatives of ten brain tumour charities, all members of Brain Tumour Research, met for our annual workshop in Birmingham. We were joined by an eleventh charity next day. The main objective was to share best practice, network, help plan for the following twelve months and review how far we'd all come since 2010.

After the AGM Brain Tumour Action and Brainwaves from Northern Ireland, each of which had contributed funds for research at The University of Portsmouth, were thanked and presented with glass plaques.

Part of the time was spent debating what is meant by the term "centre of excellence" and how best to allocate donations in the future. The structure and constitution of Brain Tumour Research was also discussed.

An audio-visual presentation offered us a virtual tour round the research laboratory at Portsmouth while a powerful, promotional film made by BTR gave patients and carers the chance to speak personally about the disease, its impact and the urgent need for Government research funding.

Individual charities demonstrated aspects of their year's work including Ellie's Fund, Levi's Star and Brain Tumour Research and Support across Yorkshire.

They have jointly been raising money for research at Leeds Institute for Molecular Medicine and have produced a delightful Calendar for 2012, among other initiatives. All the courageous models have been personally affected by a brain tumour- as patient, relative, friend or carer. Please go to <http://www.andreasgift.org.uk/> for further details.

Raise Your Hats for Research Calendar 2012





Raffle Tickets – Don't Lose Out!

We still have a few tickets left in our Grand Xmas Raffle but you'll have to be quick as the draw takes place on December 13th. It's going to be lucky for some! At only £1.00 per ticket and with some wonderful, donated prizes - top prize is a six-course dinner for two at Restaurant Martin Wishart – this is a raffle not to be missed. Contact us on 0131 466 3116 for further details.



One of Our Inspirational Fundraisers.

When born I have had brain damage of my left temporal lobe that has caused me to have epilepsy and learning difficulties since I was five and had an operation to remove a brain tumour when I was eight. As this operation did not stop my seizures, I have been living with epilepsy ever since. I am pleased that my tumour diagnosis has been re-defined as a Dysembryoplastic neuroepithelial tumour. I am grateful that cutting edge research may enable me to have further surgery to reduce the fit frequency.

As I feel able to identify with others living in a society which may not always understand what it is like to live with brain deformity, it seemed appropriate to help an organisation which has helped me. I decided to raise money by sponsorship for the 'Brain Tumour Action charity' and so I joined a group planning a trek across the Atlas Mountains in Morocco. This walk started from Marrakech to Mount Toubkal which goes to a height 4187 metres across rough terrain and high temperatures. This was challenging but exhilarating, and gave me an enormous sense of achievement, especially as I raised over £800 for a good cause in the process – highly recommended!

Matthew Herbert



Mathew on top of Mount Toubkal



"A ticket for me, please"

Donate Online

BTA has a 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 from all of us at Brain Tumour Action.

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