

head2head

Special HeadSmart Launch Edition



SAMANTHA DICKSON
BRAIN TUMOUR TRUST

Head to head with brain tumours

SUMMER 2011



Early diagnosis campaign, **HeadSmart**, launches with SDBTT founders, families and patrons.

READ THE FULL STORY ON PAGES 4-5



Brain Tumour
Awareness Month PAGE 7



Family Day PAGE 7



£10 million milestone –
an enormous success
for the charity PAGE 3

You can now donate by text! Just text **HEAD10** plus the amount to **70070**
Sign up to our new monthly newsletter by calling 0845 130 9733 or email enquiries@sdbtt.co.uk

A word from our Chairman

I am delighted to report major progress on both our patient support and research programmes. Since our last newsletter we've run six national patient support road shows throughout the UK with positive feedback from parents and families. We've also held two further family days, both with great success; to see children with brain tumours enjoying themselves with other families is a real incentive to all of us here.



These are very exciting times for our research department as we launch our early diagnosis campaign for childhood brain tumours. The HeadSmart campaign aims to reduce average diagnosis time from 12-13 weeks to less than six weeks. This campaign is very close to Angela and my hearts for two reasons. Firstly, it took nine months to diagnose Samantha and we are constantly contacted by parents and families concerned about delays in their diagnosis. Secondly, we have been involved in the research and its implementation right from the beginning in 2003. To now be in a position where it will actually start making a difference to children's lives is what we have been striving for.

Neil Dickson, Chairman

Welcome to our new CEO

We are sorry to say farewell to Paul Carbury, our former CEO, who has moved to work nearer home with an educational charity. We are delighted however, to introduce Sarah Lindsell, our new CEO, who brings with her a wealth of experience in the charity sector including senior positions at The Duke of Edinburgh's Award charity, where she had a major impact. Welcome to the team! We are also thrilled to be joined by Claire Wormley and Louise Taylor, as our new Heads of Fundraising and Marketing respectively. We know they are all looking forward to meeting you over the coming months.



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STOP PRESS • STOP PRESS • STOP PRESS • STOP PRESS

Raffle winners announced!

Thank you to everyone who bought and sold tickets in our first national raffle and helped to raise over **£19,000** towards our vital research work and patient support activities. **The Mayor of Yateley joined Angela and Neil at the SDBTT offices to draw the winners on Tuesday 31st May:**



1st Prize: £2000 - Mrs P.M. Neeves, Reading

2nd Prize: £500 - Mrs C Bailey, Leicestershire

3rd Prize: £100 x 3 winners - S Simm, Portsmouth; Mary Lang, Glasgow; A Pennington, London

Superseller winner: £500 - Mr D Hopkins, Somerset

Read more at www.braintumourtrust.co.uk/news

We remember...

All those who have lost their lives to a brain tumour, and those who have lost loved ones and friends. Our condolences go to our patron Tom Daley and his family for the loss of his father Rob on 27 May 2011. We are honoured that Rob chose SDBTT as one of his three charities for donations in his memory.

About us

SDBTT is the UK's leading brain tumour charity. We fund research that benefits children and adults and provide support and information for people who have been diagnosed, and their families. Our aim is to fight this devastating disease and give hope to brain tumour patients in the future.

Samantha Dickson Brain Tumour Trust
Saddlers House, 100 Reading Road,
Yateley, Hampshire GU46 7RX

 www.braintumourtrust.co.uk

 enquiries@sdbtt.co.uk patientinfo@sdbtt.co.uk
0845 130 9733 or 01252 749990

Patrons: Dawn French, Earl Spencer, Jonny Wilkinson OBE, Fiona Fullerton, Alastair Stewart, Chris de Burgh, Michael Crawford, Delia Smith, Stephen Hendry, Hayley Mills, Christopher Bailey, Ciara Janson, Twiggy Lawson, Martin Amis, Sandy Lyle, Leslie Thomas, Julia Somerville, Dame Helen Mirren, Sir Thomas Lighton, Gayle McDermott, Tom Daley, Seamus Cullen



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Our greatest achievements

Every year, with your help, we support around 2,000 children and adults with brain tumours and their families and carers. Here are just some of our key achievements:

- Our confidential telephone helpline service provides support to approximately 1,000 callers each year, including brain tumour patients, their family members and carers.
- Our rolling programme of information road shows supports brain tumour patients and their families across the UK, thanks to a Big Lottery grant and other funding.
- We provide family days for parents, grandparents and children with brain tumours.
- We have successfully campaigned for the introduction of the drug temozolomide to benefit brain tumour patients.
- We work in partnership with the National Clinical Director for Cancer and the Department of Health to influence policy.
- We are the UK's leading dedicated brain tumour research funder; currently funding 20 leading scientists across the UK at 17 research institutions.
- We have been awarded a certificate of best practice for our research funding processes.
- We have opened the £2.5m Samantha Dickson Brain Cancer Unit at UCL Cancer Institute; our first centre of excellence linking research to treatment.
- Our funding has enabled researchers at Newcastle University to develop a test for children who have been diagnosed with medulloblastoma, which will allow doctors to gain a much more detailed understanding of the severity of each tumour.



Above: Events from cycling to sky diving helped SDBTT reach a milestone

£10 million milestone

Samantha Dickson Brain Tumour Trust has become the first UK charity of its kind to raise £10 million.

Samantha's father, and Chairman of SDBTT, Neil Dickson said: "This is a significant milestone for us and a wonderfully fitting tribute to our daughter. The vast majority of this has been channeled into first-class brain tumour research in the UK, which has produced some remarkable results and has played a big part in shaping the current understanding of the disease. The funds have also enabled us to develop a support service which provides advice and a listening ear to thousands of patients and their carers.

When Angela and I started the charity in the dark days of 1996, we could not have envisaged what a difference the charity could make. Samantha would have been very proud. To see the research we agreed to fund five or six years ago now benefiting patients is a great incentive to raise the next £10 million. The need is as great as ever, with the disease killing more children and adults under the age of 40 than any other cancer."

Raising £10m has enabled SDBTT to do so much and we are incredibly grateful to all our supporters, donors, runners, fundraisers, Umbrella and Friends Groups, patrons, trustees and everyone in-between for helping us raise this fantastic target. Thank you all for your continued support.

We do not receive on any government funding and are totally reliant on voluntary donations for 100% of our income to enable us to continue funding vital research and providing patient support.

If you would like to make a donation to support our work please email enquiries@sdbtt.co.uk or phone 0845 130 9733 or complete the form on the back page.

HeadSmart campaign: off to a flying start



8th June 2011 marked the launch of the HeadSmart Campaign to promote awareness of childhood brain tumour symptoms among parents, GPs and other health professionals. This is a huge achievement in our work on early diagnosis, which started 10 years ago and we hope the campaign will make earlier diagnosis of brain tumours a reality for many more of the children and young people who experience them.

Our previous research has shown that it takes, on average, over three months for a child in the UK to be diagnosed with a brain tumour – roughly three times longer than in America. The longer a child waits to be diagnosed, the higher their risk of long-term disability and lower their chance of survival.

We believe that the HeadSmart campaign has the potential to make a difference in this, as it seeks to publicise the signs and symptoms of brain tumours and what parents and

health professionals should do if they are concerned about a child.

Our patrons Hayley Mills and Earl Spencer joined us for the launch at the Royal College of Paediatrics and Child Health, along with several families who have had first hand experience of a child being diagnosed with a brain tumour. The day attracted media attention from Sky, ITV, BBC, Channel 5, Radio 4's The Today Programme, Radio 5 Live and local media in London, the East Midlands and the South East.

We are very grateful to everyone who has contributed to the success of this launch, and we hope this will be just the start of a long-running campaign to raise awareness about brain tumours and their symptoms, and improve outcomes for children and young people affected.

On the front cover: **The Bubb family in Kent share their story with the media.**



Above: Harry Graham shares his personal story with the launch audience.

Below: SDBTT Patron Hayley Mills pledges her support for HeadSmart.



The HeadSmart campaign:

- A dedicated HeadSmart website consisting of information, personal stories and sources of further support: www.headsmart.org.uk
- A set of age specific symptom cards to guide parents and young people on symptoms and when they should see a doctor.
- Posters to display in GP staff rooms and in public places to highlight the campaign.
- The Diagnosis of Brain Tumour in Children Guidelines for doctors and health professionals, including when they should refer a patient for a brain scan.

The more people we can reach with our messages, the bigger difference we can make. If you would like to distribute posters, flyers or symptoms cards in your local area please email info@headsmart.org.uk.

HeadSmart partners



The campaign is the result of a partnership between ourselves, the Health Foundation, the Children's Brain Tumour Research Centre at Nottingham (CBTRC) and Royal College of Paediatrics and Child Health (RCPCH). The campaign is also supported by the Royal College of GPs; an influential organisation representing the UK's 35,000 GPs.

A wide range of health professionals, including paediatricians, GPs and neuro-oncologists have been involved in the development of the project, many of whom came together on the launch day to celebrate the start of the campaign. Thank you to everyone involved.

HEADSMART

be brain tumour aware



Above: Angela and Neil Dickson explain the HeadSmart campaign to Holborn GPs.

Below: HeadSmart lead clinician David Walker, takes questions from the audience.



Above: The official launch of HeadSmart with representatives from SDBTT, CBTRC and RCPCH.

How you can get involved

The more people we can reach with our messages, the bigger difference we can make. Here are some ideas about how you can help spread the word:

- Visit the website www.headsmart.org.uk and tell your family and friends about it – you can download or request **HeadSmart** materials to pass on to others.
- Like our Facebook page and invite your friends to like it too (www.facebook.com/headsmartcampaign).
- Help to distribute posters, flyers and symptoms cards in your area.

Please email info@headsmart.org.uk or phone 0845 130 9733 if you would like any materials to distribute.

Our sincere thanks go to the Pennell, Murray, Graham, Bubb, Lee, Floyd, Doolin, and Greenway families for sharing their stories in support of **HeadSmart**. If you would be happy to share your story for SDBTT materials and with the media in future, please get in touch with Louise Taylor (ltaylor@sdbtt.co.uk).

The HeadSmart Journey

2002 Research at Nottingham University on delays in diagnosis commences with SDBTT/Big Lottery Funding.

2005 Research results published, revealing UK lags behind other countries. Development of a guideline for health professionals on diagnosing childhood brain tumours begins.

2008 Best practice guideline 'Diagnosis of brain tumours in children' endorsed by Royal College of Paediatrics and Child Health – a major national body involved in children's health care.

2009 SDBTT joins with Royal College of Paediatrics and Child Health, University of Nottingham, Health Foundation to develop awareness raising campaign.

2011 **HeadSmart** is launched.

Be HeadSmart and make a donation today:

- Donating £20 could enable 15 families to receive a **HeadSmart** information pack making them aware of the signs and symptoms of childhood brain tumours and what to do.
- Donating £50 could enable three people struggling to cope with a brain tumour to gain the support and information they need from our National Patient Support helpline.
- Donating £100 could enable over 30 doctors surgeries to become **HeadSmart** aware; enabling them to spot the signs and symptoms of brain tumours in children and when to recommend a scan.

Please phone 0845 130 9733 or email info@headsmart.org.uk or complete the donation form on the back page to make a donation and make a difference today.

In our last newsletter we told you about six carefully selected new research grants that were awarded thanks to your support. Since then, we have funded two further high-quality paediatric research projects in a bid to help the 450 children who are diagnosed with a brain tumour in the UK each year:

Testing new drugs for common brain tumours in children

Professor Richard Grundy, Children's Brain Tumour Research Centre, University of Nottingham



Ependymoma is the third most common type of brain tumour in children, after pilocytic astrocytoma and medulloblastoma. Although the outlook for individual children varies, this type of tumour often returns following treatment, in a form that is resistant to chemotherapy drugs, and is therefore difficult to treat successfully.

A new three year ependymoma research project has recently started at the University of Nottingham, funded jointly by SDBTT and the Joseph Foote Charitable Trust. The research team,

led by Prof. Richard Grundy, is testing drugs called 'histone deacetylase inhibitors' (HDACi) on ependymoma cells in the lab. These drugs are designed to re-activate tumour-suppressor genes, one of the body's natural anti-cancer defence mechanisms, and may provide another weapon in the armory against childhood brain cancer.

Investigating key genes in high-grade brain tumours

Dr Chris Jones, Institute of Cancer Research, Royal Marsden NHS Foundation Trust

Every year around 50 children in the UK are diagnosed with glioblastoma multiforme (GBM), a type of high-grade brain tumour that also affects adults.

In a two year study, Dr Jones and his team are identifying key genes underlying GBM in children and how they work. Using a unique collection of brain tumour samples that have been removed surgically, they are focussing on genes that are present in the cancer cells in increased numbers compared with healthy cells. The findings will provide valuable clues to guide the development of specifically-targeted drugs to improve outcomes for children with high-grade brain tumours.

These new projects are important additions to the current SDBTT portfolio of adult and child brain tumour research. **To find out more or make a donation towards our research work please email enquiries@sdbtt.co.uk or call us on 0845 130 9733.**

You can find out more about all these projects and many more on the research pages of our website: www.braintumourtrust.co.uk/research

In other SDBTT research news:

- Researchers at the University of Wolverhampton have taken early steps in identifying a new drug treatment to help overcome drug-resistance in adults with glioblastoma multiforme brain tumours.
- Researchers at Queen Mary, University of London have found a genetic pattern in pilocytic astrocytoma brain tumours in children called 'microhomology', which may be involved in facilitating a key genetic change that drives tumour growth.
- New clinical trials for children with medulloblastoma brain tumours are set to commence in late 2011 / early 2012, and are using a test pioneered by SDBTT-funded researchers at Newcastle University to assign patients to different treatment groups.
- Research at the University of Nottingham has shown that non-genetic factors may be responsible for key cellular changes seen in Germ Cell Tumours (GCTs) in children, suggesting these changes may be easier to reverse than those seen in many other cancers.
- 'Clinical apathy', associated with lack of motivation and activity, can be a problem for adult survivors of childhood brain tumours, but can be treated if correctly identified, shows SDBTT-funded research at the University of Cambridge.
- Research into drug resistance and tumour origins across a range of brain tumour types in children and adults at the Samantha Dickson Brain Cancer Unit at UCL is making exciting headway.
- A scanning technique called magnetic resonance spectroscopy (MRS) may one day be used to help doctors monitor the effectiveness of treatment for children with brain tumours, reducing the need for invasive biopsies, shows research at the Royal Marsden Hospital.



Family day on the River Thames

We were delighted to be joined by over 70 people at our family day in April for children with a brain tumour and their families. We spent the day on a riverboat cruise on the Thames, followed by lunch and then games in St James's Park.

Many of the children were caricatured by a very talented artist who joined us for the trip, and others were transformed into colourful characters by our own expert face-painter and popular family support worker, Jenny Gumbrell.

The afternoon provided an opportunity for mums, dads, and children to enjoy a game of football together (dads got quite competitive!), and down time to chat in St James's Park. SDBTT staff were on hand to provide support and join in the activities.

Family days provide many benefits; an opportunity for family members to enjoy a rare day of fun-filled relaxation in the company of others who understand just what this illness means for parents, siblings and the child with a brain tumour. New friendships are made and coping strategies shared.

It costs £7,000 to provide a family day for people affected by a brain tumour. If you would like to help us provide more events like this or make a donation please email us at enquiries@sdbtt.co.uk or call 0845 130 9733.

Thank You: We are very grateful to the Roald Dahl Marvellous Children's Charity, The Waterloo Foundation and the Zurich Community Trust for helping to fund the family day and making a difference to the lives of these children and their families.

Brain Tumour Awareness Month

We were overwhelmed with the incredible response to Brain Tumour Awareness Month and would like to thank everyone who took part in a variety of events including tea parties, London to Cambridge Cycle Ride and Skydives and helped raise over £200,000.



Mass Lobby

As part of Brain Tumour Awareness Month, Samantha Dickson Brain Tumour Trust, in partnership with Brain Tumour Research, Brain Tumour UK and the International Brain Tumour Alliance held a Lobby at the House of Commons. A very big thank you to everyone who joined us to rally support from MPs for our 'Manifesto for Everyone Affected by a Brain Tumour' which has helped us to ensure the implementation of the Improving Outcomes Guidance for Brain and CNS Tumours. You can download the Manifesto and find out more about it at www.braintumourtrust.co.uk/mass-lobby-for-brain-tumour-awareness-month

Set up an Umbrella or Friends Group

SDBTT Umbrella and Friends groups give supporters the opportunity to raise vital funds for our work in the name of a loved one. We currently have 77 groups like these spanning the country. Although these groups tend to be formed under difficult circumstances, their achievements are profound and collectively, they make a huge difference to the lives of many by helping to advance brain tumour research and develop patient and carer support. It's easy to set up your own Umbrella and Friends group with our 'starter information pack' and we are on hand to provide on-going support.

If you are interested in setting up an umbrella or friends group, would like more information or have any questions, please email umbrella@sdbtt.co.uk or call Louise McNutt on 0845 130 9733.

Here to help

If you would like to talk to someone about you or your loved one's diagnosis, or would like more information about the different types of tumours and possible treatments, please call us. Our friendly, impartial and confidential support helpline provides a listening ear from people who understand your situation. Finding out more about the illness and talking things through can help you feel more in control.

Call Roz Osborne or Jenny Gumbrell on 0845 130 9733 or email patientinfo@sdbtt.co.uk

How you can help

Run or cheer for team SDBTT

Each year, we have places for a host of running events including the Virgin London Marathon, Bupa London 10,000, the Asics British 10k London Run and the Royal Parks Half Marathon. When you become part of Team SDBTT, we will support your training and fundraising every step of the way. If you would like to take part in a different UK or overseas run, you can still join Team SDBTT by signing up to raise funds on our behalf and we will support you just the same.

If you don't fancy a run in the park, then perhaps you would like to join our **SDBTT Cheer Squad**. At each event we need a team of supporters to cheer our runners along the way and help them to the finish. Our **Cheer Squad** are just as important as our running team so please join us if you can.

Please join our Team SDBTT Running or Cheer Squad by emailing enquiries@sdbtt.co.uk or calling 0845 130 9733.



Fundraisers in the spotlight

As usual, hundreds of you have been busy raising money in lots of different ways to help support our vital work. Thank you to everyone for your efforts including:

Doreen Mills, who organised a sponsored 6 mile walk, Hayley's Walk, in Liverpool with 100 participants in fancy dress and purple balloons that were released to the sky! Thank you so much to the Hayley Mills Fund who raised over £5,000 for us through the walk.

Rob Martineau has successfully completed the Cape Town to Addis Ababa cycle has now raised £20,722 in memory of his father. SDBTT would like to thank Rob for his incredible effort and achievements.

Tania Love, who was inspired to do something for SDBTT after the tragic diagnosis of her Aunt Verity and her friend and colleague Richard to brain tumours. Tania signed herself up for a whole series of runs in support of SDBTT and has raised £1,910 through generous sponsorship by her friends and family. Thank you so much.

If you would like to raise funds or know anyone who would please email enquiries@sdbtt.co.uk or phone 0845 130 9733.

Calling volunteers

Are you looking for an opportunity to do some hands on work for an extremely valuable cause? We need your help! We need volunteers to help with everything from office administration, hands on work at our fantastic events across the UK, or helping us to spread the word by delivering posters and leaflets to your local community. If you are able to help, we would love to hear from you. Please contact enquiries@sdbtt.co.uk or call 0845 130 9733. Thank you!

I would like to help fund critical brain tumour research and vital patient support

Here is my donation of:

£20 £50 £100 Other £ _____

Please find my cheque/CAF cheque/postal order, made payable to **SDBTT**

OR Please debit my credit/debit card

Card number: _____ (Maestro only)

Expiry date: Issue no. (Maestro only)

Signature _____ Date _____

Name (Mr/Mrs/Miss/Ms): _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

I am happy for SDBTT to contact me by email.

Please also let us know if your contact details have changed.

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giftaid it Make your donation worth 25% more at no extra cost to you:

Please treat the enclosed gift, and all gifts of money that I have made in the past 4 years and all future gifts that I make from the date of this declaration as Gift Aid donations.

To qualify for Gift Aid, you must pay an amount of UK Income Tax and/or Capital Gains Tax at least equal to the amount of tax that SDBTT will reclaim on your donations in the appropriate tax year (currently 25p for every £1 given).

Five ways to give:

- 1 Complete this slip and post it to: **SDBTT, Saddlers House, 100 Reading Road, Yateley, Hampshire, GU46 7RX**
- 2 Call **0845 130 9733**
- 3 Text **HEAD10 plus the amount to 70070**
- 4 Email enquiries@sdbtt.co.uk
- 5 Web www.justgiving.com/sdbtt

Sign up to our new monthly newsletter

Call 0845 130 9733 or Email enquiries@sdbtt.co.uk

Thank you for your support!

The personal information you provide will be held securely in accordance with our internal policy and the Data Protection Act 1998.

Please tick this box if you would prefer not to receive mailings from us.

