

TARGET

News from the UK Brain Tumour Society

Issue 9 Spring 2004

FAST FORWARD



Spring heralds in fresh vigour and a renewed determination by UKBTS to pick up the challenge presented to us by brain tumours. Echoes of the positivity UKBTS hears from our supporters will reverberate through all we do this coming year.

Zoë Hoppe, Director UKBTS

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*Individual views expressed in articles
are not necessarily those of UKBTS.*

Please contact the UKBTS office if your name and address details are incorrect, or if you do not wish to receive Target. If you would like to be added to our mailing list, please let us know.

UKBTS has arrived in Cumbria

Jane Stephens and UKBTS can now be contacted at UKBTS, 6 Queen Street, Whitehaven, Cumbria, CA28 7BB
Tel: 0845 4500 386
Email: info@ukbts.org.uk
Website: www.ukbts.org.uk

UKBTS

THE UK BRAIN TUMOUR SOCIETY
Registered Charity Number 1068338

Track One: a new Board

Following an extensive and selective recruitment initiative, UKBTS now boasts a diverse and well-balanced Board of 9 Trustees. Dip into page two of this issue and you will get a real sense of the "goody bag" of resources we now have to drive the charity forward. We are confident we have a team that will ensure we do things in the right way and that we do the right things!

Track Two: regional fora

We are off to a good start with our plans to get out and about, running two highly successful Regional Fora with over 50 participants in London and the West Midlands. Watch our website for news of our next regional meetings. The resonant message is the importance of 'Living well with and despite the brain tumour'.

Track Three: website launch

July will see the launch of our brand new website, which will evolve to provide a one-stop shop for information and support '24/7'.

Track Four: conference

This summer highlights UKBTS' 5th Annual Educational Conference. The theme will be, "The Scientist, The Doctor and the Patient," and will focus on treatment and care.

We are delighted to have input from leading specialists, both national and international and to have Mike Traynor to give the inaugural Peter Best Memorial lecture.

Track Five: Brain Tumour Awareness Week

The conference will kick-start our first ever Brain Tumour Awareness Week. This will take place from 10-18 July and will feature fundraising and media events throughout the UK.

Paul Nichols

Paul Nichols retires as Chair of UKBTS due to ill health. We are very sad to lose him. His stewardship of the charity over the past year has been invaluable. On joining us as a trustee over 2 years ago, he expressed the desire



to apply his experience in business to help organise a charity. He has achieved that and lots more! We wish Paul and his family health and happiness.

UKBTS 2004

CONFERENCE

THE SCIENTIST, THE DOCTOR

AND THE PATIENT

**12th and 13th July 2004,
Nottingham University**

Booking form enclosed or please apply to:

Jane Stephens, UKBTS, 6 Queen Street, Whitehaven,
Cumbria CA28 7BB

Tel: 0845 4500 386 Fax: 0845 4500 386

e-mail: info@ukbts.org.uk

or enquiries@ukbts.org.uk or jane.stephens@ukbts.org.uk

UKBTS, working to conquer brain tumours through education, research and support.

All aboard!

Meet the UKBTS trustees

As you will see from the brief personal introductions to follow, UKBTS has been repaid a hundred-fold for moving out of its comfort zone!

Nigel Boutwood

As the longest standing trustee of UKBTS I now assume interim chairmanship of UKBTS following the untimely retiral of Paul due to ill-health. Nigel is Chairman of the Trustees of Charlie's Challenge. A founding Trustee of UKBTS, he is married to Nettie. They have three children and live near Heathfield in East Sussex. Nigel is the Managing Director of an advertising and marketing agency in Eastbourne.



Graham Sopp

I am very excited about starting to implement UKBTS' well thought out strategy and I look forward to seeing the improvements. I've spent a lot of time managing change during my 20 years' business experience and I think that will be useful. I was delighted to find UKBTS - it's a great cause with great trustees.



Angela Deacon

Angela is a solicitor and widow with 2 grown up sons running her own business "For 25 years everything was going swimmingly when my husband was struck down with a brain tumour very malignant (grade 4) which took his speech away then his mobility and finally his sight There was very little information I could find about brain tumours and my GP had never dealt with one so it was a steep learning curve. I amassed as much information I could about brain tumours while caring for my husband. I now want that information (and correct information) to be there for all patients and carers...without the battling!" As a lawyer Angela hopes she can contribute. Although not well versed in charity law she is confident that she would know where to look and who to approach. She looks for the time when these tumours can be cured She would like the charity to grow so that the public are aware of the condition of brain tumours and wish to contribute to finding a cure. She is passionate that all patients are treated with dignity and are given the full facts



Ella Pybus

I have experience of living with a brain tumour. My motivation for choosing to act as a trustee for UKBTS comes from my sense of frustration over the treatment of and support for people with brain tumours. Many of the difficulties patients face could be overcome by more investment in research, having more specialists and better NHS aftercare. I want to see the same success in treating brain disease as has been seen in cancer care. I am excited by UKBTS' determination to work hand-in-hand with the medical profession towards better treatments, and to provide support and information across the country.



Elizabeth Eves

I am delighted to become involved with the UK Brain Tumour Society. I have personal experience of a Pituitary Tumour. I have been working in the charity sector as a Supported Needs Coordinator for six months, and as a volunteer for over 10 years. As a Medical Sociologist I have a strong interest in service provision for neurology patients. I am actively involved in researching local community health needs in Southwark through the Patients Forum, and I would like to develop this by working with a national charity. UKBTS has a very positive outlook and has the potential to be the leading organisation in the field in terms of good practice and research.



Maria Christidou

Maria became a trustee of UKBTS at the beginning of 2000 while she was still in university studying Health Psychology. Since then she has watched the charity grow and many volunteers being involved in fundraising activities and support. Maria is originally from Greece but currently lives in Portsmouth and works in a medical communications company in Basingstoke. Her aim is to raise awareness of brain tumours; She is also interested in medical research looking at the causes and management of brain tumours. Maria takes a lead role within our support services.



Just before Christmas 2003 UKBTS embarked on a courageous venture to recruit new trustees.

'We were looking for 'legal, political, human resource, fundraising and governance expertise' said Zoë Hoppe, Director of UKBTS, 'We were searching for people with knowledge and understanding of the NHS, Social and Health Care systems.'



Julia Oliver

Twelve years ago I had a large meningioma on the brain stem that was successfully removed at The Maudsley so when I saw the advert for UKBTS Trustees I knew I had to apply. I remember how much my family suffered with little or no support when I was diagnosed and I want to make a difference. My background is Human Resources so I hope to be able to help UKBTS with organisational questions and recruitment. I have worked on a number of Boards for charities previously so I am also interested in strategic thinking and business planning. I am pleased to be involved with UKBTS at such an exciting time.



Elizabeth Preston

Elizabeth is Assistant General Manager for Surgical Services at NHS Lothian University Hospitals Division in Edinburgh, where her responsibilities are for the Cancer Centre, Neuroscience and Musculoskeletal services. Elizabeth is a neurosurgical nurse by profession, having trained at Guy's Hospital, London & Addenbrooke's Hospital, Cambridge. She was enthusiastic to become a trustee of UKBTS as a result of reading TARGET. She hopes to contribute to the success of the charity through communication and improved services for patients and their families. "I have a desire to ensure that patients and their families receive the optimum care and treatment regardless of location in the UK, borne out of personal and professional experience in the speciality. I hope that my breadth of NHS experience and network of contacts will prove useful to UKBTS and I look forward to driving the charity forward to achieve its aims"



Kelly St Claire

I currently work with The MedicAlert Foundation heading up the Marketing Communications department. This was my first role within a charity and has led me to seek a Trustee position in a voluntary capacity to help in the best way I can. Following several instances of brain tumours within my family, the UKBTS was an obvious choice. I hope to work with the UKBTS team to build and develop awareness of the organisation in order to further research into the condition and ensure that the best possible treatment, care and support are available to those with the condition.



News and views from the brain tumour community

The Meningioma Association UK

The Meningioma Association UK offers support and information to anyone affected by this kind of tumour. It was set up in 1999 when Carolien Batt, Ella Pybus and Kathee Myers met.

Three different nationalities came together, Dutch, English and American; each driven by personal experience to do something to overcome the isolation of being diagnosed with a brain tumour. Unfortunately, Kathee withdrew due to post-op problems, so Carolien and Ella determined to set up a British support group. This year they were joined by former spinal meningioma patient, Jane Casswell.

Telephone and email support are available, and since last summer there is a website which is updated regularly. The group also publish a twice-yearly newsletter for members. Their aim is to develop support and reach out to everyone whose life is affected by meningioma whether they be patient, partner, family or care-giver.

The association gladly works with UKBTS and AMNET to extend support to all those affected by brain tumours.

Contact The Meningioma Association UK, 53 Pine Grove, Brookmans Park, Hertfordshire, AL9 7BL,

tel: 01 787 374084

email: meningiomaUK@aol.com

website: meningiomaUK.org

Brain Tumour Action

Brain Tumour Action hosts a popular email discussion forum or 'virtual support group' on its website www.braintumouraction.org.uk. The aim is to provide a means of communication and support, especially to those patients and carers who live in areas of the UK where there is no local support group.

Visit the website to see for yourself. You've got nothing to lose and everything to gain, including new friends and the chance to say exactly how you feel.

Lorraine Mackenzie, Chairperson, Brain Tumour Action

LOCAL SUPPORT

Brain Teasers

If you are a young person with a brain tumour, you are not alone

In September 2001 I was diagnosed with a brain tumour, and at the age of 25 I felt like my world had collapsed around me. As well as the feeling of fear, I had an overwhelming feeling of loneliness. Was I the only young person with a brain tumour?



The only other people I had seen in the waiting rooms were a lot older than me. I found myself looking for answers to questions that no one I knew could answer. I needed someone to turn to who was in the same position as me, and facing the same anxieties at such a young age. It was then I was introduced to the **Brain Teasers** group and realised I wasn't the only one suffering these feelings and I found answers to many of my questions.

The **Brain Teasers** group was established in April 2003 by ten young brain tumour patients, with the help of Neuro Oncologist Specialist Nurse, Rachel MacArthur, and the team at the Richard Dimpleby Centre at St. Thomas' Hospital. The group continues to grow, through word of mouth, and with new patients being diagnosed at the hospital.

The fortnightly meetings cover many subjects including treatment, side effects, complementary therapies and benefits advice and these discussions are made easier through the various guest speakers who have kindly given informal presentations to our group.

To find out more, please come along to the Richard Dimpleby Centre at St. Thomas' Hospital, London, or call us Edward, and Kerry Foster-Mitchell on 020 7960 5721 and we can have a chat.

Doncaster Support Group

Hi, my name is Gail, I am 39 and I have an inoperable brainstem glioma, diagnosed in 1996. After finding out though personal experience, that any support or information available to adults and their families was rather lacking, I decided to set up a support group in my home town, Doncaster. This idea took till last year to come to reality.

The group has met twice and at the moment we have 8-10 members. The meetings take place every third Wednesday in the month, for support, information, guest speakers and social interaction. Our group is open to patients, family members, carers and anyone who has been touched by this disease, either personally or otherwise.

Hopefully, awareness of the group will increase as my computer skills improve (from one finger to two) and numbers will steadily grow.

Gail Swindell

For more information, contact Jane Stephens at the UKBTS office.

SDRT Spotlight

COMMUNITY FUND

Due to the success of this year's fundraising 25 research applications were received from all over the UK, and the SDRT will be funding 6 of the top marked projects in the spring. Each project will be reviewed by all 16 members of their Scientific and Medical Advisory Board, along with a minimum of four external referees, who are experts in the field of neurology from the UK, Europe, Canada and the USA, for each project.

It is the huge support of so many professionals in the field, and the rigorous system used for the grant round that has enabled the SDRT to become so successful. Already one of their earlier projects has progressed to clinical trials at three London Hospitals.

Life, love and laughter

Taking care of yourself

Sometimes as patients and carers we can feel helpless in the face of a brain tumour diagnosis. However, there are areas of our lives where we can take full control and help ourselves to a better quality of life. For example, we can make choices about the food we eat. Here Dr Bali Rooprai offers her suggestions for 'diets that fight cancer'. Dr Rooprai is Principal Lecturer in Neuro-oncology at the University of Portsmouth.

Ten steps to help your body fight cancer

1. Wash, dice and extract juice from **3 carrots** once a day (don't peel).
2. Take a teaspoon of powdered peel from **oranges or tangerines** mixed into your carrot juice (wash and dry the peel and grind in a coffee grinder). **Or** drink the juice of one small orange including peel and pips.
3. Take a teaspoon of concentrated **aloe vera** daily in fruit or carrot juice (Boots/other health stores)
4. Take **selenium** supplements – 200 micrograms per day for adults or less than half this for children. (Boots/other health stores)
5. Take one **red grape seed extract** capsule per day (email Dr Rooprai for details on how to obtain this bali.rooprai@port.ac.uk)
6. Take **one eighth** of a teaspoon of **turmeric** daily at bedtime in a teaspoon of honey.
7. Add plenty of **tomatoes** to your cooking or buy Lycopene and take 25mgs per day.
8. Include **soya** in your diet once a week.
9. Drink **green tea or rosemary tea**.
10. Take one daily **multivitamin with minerals** tablet.

For other useful and interesting diet and nutrition ideas to help your body fight cancer check out these websites:

www.bristolcancerhelp.org
www.cancerhelp.org.uk
www.cancerbacup.org.uk

One of the easiest and quickest ways to cook yourself something nutritious, healthy and tasty is to have a go at making soup. This recipe is adapted from the Cancer Research UK website (www.cancerhelp.org.uk), where they also have other suggestions for healthy eating.

Vegetable soup

Serves 8 (depending on appetite!)

- 1 medium carrot – peel it and chop into cubes
- 1 medium onion - chopped finely
- 1 large potato – peel and chop into cubes

1 1/2 pints stock (a vegetable stock cube is always handy)

1/4 cabbage - shredded

1 tomato - chopped

pepper/parsley (if you like it, if not why not try a different herb eg basil is nice with tomato)

You could also add other vegetables, depending on what your favourites are eg leeks, parsnips or other root vegetables.

1. Place onion, carrot, potato and stock into a large pan.
2. Bring to the boil and simmer gently.
3. Add cabbage and tomato.
4. Simmer for another 30 minutes or until vegetable is just tender.
5. Season with pepper and parsley.

You can increase the fibre content by washing the carrot and potato but leaving the skin on.

Laughter reduces stress

A woman went into hospital and gave birth to twins. Afterwards she was so exhausted she fell into a deep sleep. When she woke up her consultant was at her bedside. 'I have good news' she said, 'you had twins, a boy and a girl. Your brother has registered their names! 'Oh no', said the woman, 'my brother is so daft! What on earth has he called them?' 'Well' said the consultant, 'the girl is called Denise.' 'Oh, that's not so bad, thank goodness, what about the boy?' 'D nephew!'

Computajoke stress

What did one keyboard say to the other keyboard?
Sorry, you're not my type.

Helpline? I've just pushed a piece of bacon into my disk drive!
Has the computer stopped working?
No, but there's a lot of crackling.

We would like to make this a regular feature so, if you have any jokes or recipes you would like to contribute, please send to Jane Stephens at the UKBTS office.

Lives that inspire

In Memoriam:

Alan Jones

Alan Jones was just an ordinary bloke in an ordinary little town, but he was very special to us. He was a Dad to Daniel and Christina, a husband to April, a son to Ray and Betty and a brother to Linda and Lorraine. All of us loved him in our own special ways.



One day, just before Christmas 2001, Alan was at work undergoing his annual review when he suddenly realised he could not write or speak. His boss managed to get him to the local hospital in Hereford, where a stroke was diagnosed and he was allowed home for Christmas with some aspirin. However, his condition deteriorated quickly – he was experiencing minor fits and then terrible, excruciating headaches. We rushed him by car to hospital in Birmingham (there were no ambulances available, a constant theme!) where he underwent brain surgery and was diagnosed with an inoperable Grade IV glioblastoma multiforme. We will never forget that day.

Just 8 months later Alan died aged 39, surrounded by his family, in St Michael's Hospice, Hereford. Though in many ways those 8 months were the most terrible of our lives, we also had many happy and funny moments, including a holiday to Disneyland, Paris. Even in the hospice Alan was still joking and teasing his kids. He often wore a baseball cap with his name on and one day his cousin asked him if he wore it in case he forgot his name. 'Oh yes,' he said, 'if I forget I look in the mirror and I can see my name is NALA!'

Towards the end of his life two outside things were very important to us as a family. Firstly the hospice, which strangely felt like a glimpse of paradise after so much inadequate 'support' from the NHS, and secondly UKBTS. We discovered UKBTS very late on and wish we had known of it earlier. We very much hoped to attend the annual conference in 2002 but Alan was just too sick by then. Jane Stephens of UKBTS was a real cornerstone of support all that summer.

So, when by the following spring, we were planning to launch a Fund in Alan's memory the obvious beneficiaries were UKBTS and the local hospice. We began by holding an Open Garden with Tarrington Brass, a local band. Alan had played the cornet and Tarrington Brass played at his funeral so this seemed particularly apt. The local paper, the Hereford Times, was extremely helpful and featured the event. Since then we have also held a Christmas concert with a local group, Off Broadway, and we are planning a variety of fundraisers over the next year.

As Daniel, Alan's son, said, 'It was very hard to help at the Open Garden. It reminded me so much of Dad and I wished I didn't have to do it. But I wanted to do something to show that I cared. When I saw all the people pouring through the gates I knew they cared too.'

Like so many other fundraising groups that support UKBTS we set up the Alan Jones Memorial Fund to remember a family member, to keep his name alive and to try to ensure that others in the future don't have to go through the same things. Alan continues to inspire us and drive us on with his humour and his courage.

(Donations may be made to Alan Jones Memorial Fund, c/o Mrs Lorraine Smith, The Old Cedars, Much Birch, Hereford HR2 8HR).

IN LOVING MEMORY

UKBTS has received many kind donations over the past few months from family and friends, in memory of their loved ones.

Maurice Amos
Graham Crutch
Glyn Turbin
Catherine Sweetnam
Douglas McVeagh
Luke Frost
Mark Turner
Peter Newland
Hubert Newland
Mary Gowland
James Jeffs
Jo Gould
Ivan Bridge
Bob Deacon
Arthur Williams
Andrew Mattocks
Carl Palmby
Daniel Isaacs
Douglas Short
Alex Fryer
Jill Hasan
Peter Best
Sheila Fielding
Hilary Parker
Mary Gowshall
Eryl Hughes
Lilian Gibbins
Rosemary Burtonshaw
Pauline Broomhead
Alan Jones
Greg Power
Lorraine Ellis
Colin Lawrence
Peter Norris
Michael Bailey
Emma Brett
Matt Wood
Mark La Valette-Robins
Ivan Bridge
Susan Barnshaw
Matthew Fryer



Introducing UKBTS' newly appointed Fundraising Manager

Anne-Marie Dickinson first became aware of UKBTS when her friend and ex-England fast bowler, Alan Igglesden, was diagnosed with an inoperable brain tumour.

Anne-Marie comes from a varied sales and fundraising background and hopes to bring both her skills and enthusiasm to the charity and raise awareness and support within the community.



GREAT SPORTS!!!! Celebrity Patrons

David Gower OBE

Ex-England cricketer, David began his career with Leicestershire in 1975. He was first Capped in 1977 and served as Captain from 1984-86 and then again from 1988-89. He played for Hampshire between 1990-93, being Capped again in 1990. David remains the second highest test runs scorer for England and in 1992 received an OBE. Now a broadcaster and journalist, David spends most of his time hosting SKY's coverage of international cricket.

Mike Gatting

A former England Captain, Mike Gatting was a prolific batsman for both his county and England. Having experienced mixed fortunes on and off the pitch, Mike's greatest achievement was skipping the side that retained the Ashes in 1986-87. He retired from playing at the end of the 1998 season and coached Middlesex for two seasons. Mike is now a regular in the BBC Test Match Special commentary box during the summer.

Barry McGuigan MBE

A true boxing champion, Barry McGuigan fought his way to the top of his profession, becoming European and WBA Featherweight Champion of the World. Boxing since the age of 12, he went on to fight more than 120 times, winning a Commonwealth Gold in 1978. In 1980 Barry turned professional, becoming British and European Champion in 1983 and WBA Featherweight Champion in 1985. Since his retirement in 1989, Barry has been delivering boxing commentaries all over the World. In 1994, he was awarded an MBE.

Lashings Cricket Club support UKBTS!

"Lashings" the celebrity cricket club, which boasts players such as Sir Viv Richards, Brian Lara and Phil Tufnell - to name but a few - will be playing in aid of UKBTS at Moat Park, Maidstone on Friday, 20 August. Furthermore, the day will be followed by a Celebrity Ball at The Ramada Hotel, Maidstone, where more than 30 celebrities will attend in a show of support. The day is still at the early planning stages, but you can put your name forward now to reserve tickets or simply receive further information, when available.

Contact Anne-Marie on 01959 563003 or by email at annemarie0205@aol.com.

King of the Jungle

Tuffers takes a swing for UKBTS

Sporting celebrity, Phil Tufnell, swung by Westerham Golf Club in October in a show of support for fellow ex-England cricketer, Alan Igglesden.



Alan Igglesden Golf Day

Alan's 5th Golf Day in aid of UKBTS will take place on Thursday, 30 September at Westerham Golf Club in Westerham, Kent. Last year's event was attended by Phil Tufnell and a host of cricket celebrities, who will be back this year to beat last year's fundraising efforts. The event is growing in popularity each year. If you would like to join us on the day or take up one of the many sponsorship options available, contact Anne-Marie - details as before.



Marathon Runners!



Five dedicated runners took to the very wet streets of London to raise money for UKBTS, this year. The day couldn't have been wetter, but we understand from our runners that it was better for them than the thousands who lined the streets to cheer them on!

Carol Bide: Carol is a retail manager from London. She has previously run the London Marathon but had to watch the race from the Atkinson Morley hospital last year, as she recovered from surgery for a brain tumour.

David Christie: David is a teacher in Surrey and ran in memory of his friend, Michael Norton. David has received fantastic support from his friends, colleagues and pupils having put together a great fundraising package!

Rob Golby: Rob, an accountant from Kent, is a friend of Alan Igglesden - a regular UKBTS supporter. Alan is currently battling with a tumour and Rob hopes his efforts will not only have helped raise awareness for the charity, but will also inspire others to lend their support.

John Attewell: John is another teacher from Surrey and ran in support of a good friend, who has recently been diagnosed with a brain tumour. John hopes to have raised both money and awareness for the charity.

Peter Hamling: is a Company Director from Inverness, who runs with UK Athletics Affiliated Club, Lochaber. Peter ran the Marathon as a 50th birthday present to himself and is keen to raise as much as he can for UKBTS.

We extend our sincere thanks to them for the dedicated support they have given UKBTS.

YASH TRUST

In Association with UK Brain Tumour Society

Yash Trust was set up in memory of my husband, so that we could raise funds for further research into treatment of brain tumours.

Our inaugural event, a dinner dance, was held in October 2003, at Heathrow Radisson Edwardian Hotel and was attended by 350 people.

During the evening, speeches were given by Professor Geoff Pilkington and an oncologist from Charing Cross Hospital, Dr. Glazer.

As a result of the evening we raised £6,000 for UKBTS which will be presented to them at our next event.

Further events will be planned soon - watch this space.

Bali Gill



Read about some of the many wonderful activities that have raised vital funds for our work. Sadly, lack of space prevents us from including everything, so a huge 'thank you' to you all – and apologies if your event isn't mentioned.

Take up The UKBTS Ben Nevis Challenge!

Join us for a fun filled weekend amongst some of the most beautiful and dramatic scenery in the world and ascend Britain's highest mountain, whilst raising vital funds for UKBTS.

Over the weekend of 24 September, we will be taking a group of walkers (there is no climbing involved) on a sponsored ascent of Ben Nevis, Britain's highest mountain at 4,408ft!

We have chosen the 'Mountain Track'; ascent by this route takes around 8 hours - 5 up and 3 down! Any normally active person should have no problem in reaching the 'roof of Britain' from where, on a clear day, there are spectacular views over the Western Isles of Scotland.

If you would like to take part in this event, please contact Anne-Marie on 01959 563003 or Lisa Cassidy on 01942 826256.

We hope to see you there!

Carol Singing at Waterloo

At 4.30 on December 23rd, a small group of friends, colleagues and family joined me in braving the wintry evening to huddle under the Christmas tree at Waterloo station to sing carols and try to charm some money from the passing commuters.

There was a slightly frantic feel in the air as it was almost the last shopping day before Christmas, and the crowds rushed past at a remarkable rate. It was hard to make ourselves heard over the noise of the trains and public address system; and while my mother's suggestion that we take over the tannoy in order to amplify our singing was ingenious, it was not really practicable.

We persevered, however, and over the course of an hour and a half's singing, we managed to collect £110 for UKBTS. I would like to thank Elaine Brown for joining a group of unfamiliar people to shake a bucket for us and Bruce Dafforn-Jones, who took photographs. I would also like to thank the kind man who donated his office's copper collection, weighing down the bucket but augmenting our total.

I hope we will be able to do some more 'musical fund-raising', so if there are any UKBTS volunteers out there with musical talent, please let me know

Alix Griffiths - alixgriff@hotmail.com

SDRT Spotlight

The Samantha Dickson Research Trust had a record year raising £500,000. Fundraising in 2003 included a Charity Ball at the Dorchester, London which raised £131,000, a Beat Fashion Show at Marlborough, their fourth Celebrity Cricket Match and fifth Celebrity Golf Day, together with events held by supporters throughout the country - all helping to boost funds for brain tumour research.

Some Forthcoming events

For News of other Forthcoming Events within the brain tumour community contact Angela or Karen on 01252 627426 for SDRT events; Michelle Fisher on 01296 730230 for Ali's Dream events and Gillian Thistlewood on 0208 336 2020 for Brain Tumour Foundation events.

Dates for your diary:

6th June

Poole 10k road race 10am

available. Tickets available at the gate at around £7 each.

This afternoon will be followed by:

10-18th July UKBTS BRAIN TUMOUR AWARENESS WEEK

Wear a hat and let us have your photos of where, when and how you wore it. The best photo/innovative idea will win a prize.

20th August

Lashings Summer Ball – Ramada Hotel, Maidstone

Lashings have again offered their valued services – this time for a celebrity ball, which will be held on the evening of the cricket match. In total some 35 celebrities have agreed to attend the event. The entire proceeds of which will go to UKBTS. Tickets are £125 each and can be ordered now. The evening promises to be unforgettable, so if you want a chance to mix with the stars, please order your tickets soon!

10 July 2004

"The Geoff Freeman Memorial Ball"

Mark Freeman and friends are hosting their annual Charity ball on Saturday 10 July at The Cricket Ground, Ashorne, Warwickshire, in memory of Mark's Dad, Geoff. Guests can enjoy a live band, buffet supper and a grand prize draw - all for the price of just £28. In addition, the event has taken up UKBTS' 'Bad Hatters' theme and guests are invited to wear hats - there will be a prize for the best (or worst) one! Tickets are available by contacting Mark on 01789 840504 and proceeds from the evening will be split jointly between UKBTS, A&MMCC and Myton Hamlet Hospice (Warwick).

26th September - Great North Run

We have several participants and you can sponsor them on line on the JustGiving Website.

12/13th July

UKBTS Nottingham Conference.

30 September

Alan Igglesden UKBTS Charity Golf Day – Westerham Golf Club, Kent

Alan's 5th Golf Day has been confirmed at Westerham. 25-30 teams of 4 will play for charity with prizes for best team, best individual player and best ladies score, in addition a yellow ball competition, longest drive and more! Team entry costs £375 and includes breakfast and a two-course meal, when a raffle and an auction will take place. Bookings are now being taken, but get in early – we always sell out!

17th July

Bad Hatters Tea Party – West Midlands

An informal evening; we have yet to confirm the venue, but we hope to provide guests with live music and a buffet. "Come as you are, but wear a hat" ticket price TBC.

October 1st

The Peter and Gaynor Best memorial Golf Day

The first memorial golf day in loving memory of Peter and Gaynor, two of the nicest people you could meet.

17th July

Claygate Flower Show

Please contact Jane at UKBTS office for further details

Please contact Jane at UKBTS office for more details

20th August

Lashings CC v Ex-England XI – Celebrity Cricket Match, Moat Park, Maidstone, Kent.

November 27th

Charlie's Challenge Ball

Please contact Jane at UKBTS office for more details

Celebrity cricket team, Lashings, based in Maidstone, have agreed to play in aid of UKBTS and spectators will have the opportunity to see some of the greatest cricketers the sport has produced. Alan Igglesden will be putting together an Ex-England side to take on Lashings for this afternoon event, which should be a great family afternoon. Refreshments and a BBQ will be

To put your name down for any of the above events, please contact Anne-Marie on 01959 563003 or email at annemarie0205@aol.com or Jane Stephens at the UKBTS office on 0845 4500 386.

Our sincere thanks go to the following for their invaluable and continued support of our work.

Matthew Edelsten
Rupert Dyke
James Deacon
Angela Deacon
Alan Igglesden

The Theatre Royal Norwich
Mike & Clare Ashley
Ed Hopkins
Kath and Lucy-Kate
Newland

Helen Williams
Bungay Cricket Club
Ken and Judie Fryer
Gill and Chris Wood
Leicester & Rutland Veteran

Ladies Golf Association
Friends and family of Lois
and John Reeve
Sutton Valance School
Solomon Nicholson

Mr & Mrs Blandford
Matthew Turbin
Adrian Fielding
Andy Parker and family
Janice Crutch

Mr & Mrs Norris and family
Alan Jones Memorial Fund
Paddy McShee and friends
Deborah Collins
Bali Gill

Action Stations

London and the Midlands speak out

UKBTS is committed to developing local and regional groups. The aims are:

1. To give support to patients and those close to them
2. To raise awareness and funds
3. To improve local services
4. To reduce isolation

Two Regional meetings have already taken place - others are planned. Here is a summary of discussions on the action needed.



Jon Young presents ideas on Information needs put forward by participants at the London Regional Meeting.

information and support

Information equals support - patients have the right to accurate information

Inform doctors, help them to be more sensitive

Improve speed of diagnosis and information at time of diagnosis

Run a public and medical information programme

Financial information very important

Information on diet, nutrition and complementary therapies

Information about support groups

Training for volunteers – nurture their skills!

Good database

communication

Revise UKBTS leaflets and distribute widely

UKBTS website is crucial

Need for nationwide coordination

Use the media to spread information

Share our ideas

Communicate – web, email, phone, post, Target newsletter

'Twinning' or 'buddy' system for people living with tumours

Improve resources for volunteers

awareness raising

Hold themed nationwide events

Use local radio and press

Contact the hospice movement

Find a celebrity patron or personality

Wear badges with UKBTS logo

Improve website

Contact MPs

Hold Brain Tumour Awareness Week

Review UKBTS image and logo – improve

fundraising

Sponsored events, sports, walks, swims, dances and so on

Attract legacies

Advertise

Raffles

Race nights

Celebrity calendar

Christmas cards

Business sponsorship

Collections, crafts and coffee mornings



Jan Young, Zoë Hoppe, Jane Stephens, Jon Young in discussion at the London Forum meeting



Harvey Bass, Kathy Jones, Alix Griffiths (forefront) Rachel MacArthur, Jan Nichols, Jane Stephens (background) at the London Forum meeting



What will UKBTS do as a result of these days?

1. UKBTS will review its corporate image and logo.
2. UKBTS will produce a new range of marketing and information leaflets.
3. It will employ a fundraiser to embrace the enthusiasm of the regional groups and apply for funding to employ a national manager to coordinate volunteer effort.
4. UKBTS will upgrade and improve its website and Target.
5. It will improve its database.
6. It will set up effective internal communications for regional fora and supporters.
7. It will seek additional funding to support regional initiatives.

These first two regional days have been incredibly useful and productive. I look forward very much to the next in the series and to working with you all again.

Zoë Hoppe, Director, UKBTS.

UKBTS, working to conquer brain tumours through education, research and support.

RESEARCH

Cutting-Edge Research into Brain Tumours

Brain tumours are estimated to be the 10th most common form of male cancer in the UK and around the 12th most common in women. There are between 7 & 8,000 new cases every year and very little is known of why and how they occur and what treatments can be most effective.



Dr John Darling

Professor John Darling has been at the University of Wolverhampton for just over a year and joined from the Department of Neurosurgery at the Institute of Neurology at University College London, where he worked on brain tumours in both children and adults.

His research primarily involves adult tumours and investigating their genetic makeup. One of the most malignant tumours is known as glioblastoma multiforme.

"Glioblastoma is bad news," explained John, "if you don't have treatment you can die within weeks. Even if you have an operation to remove the tumour, there is a likelihood that cells will remain elsewhere in the brain and return. "There are few very long-term survivors, but in patients who have a combination of an operation, radio and chemotherapy, the percentage of two-year survivors goes up.

"What we are looking at is the biology of these tumours and by learning more about the biology, we may be able to predict which patients would react better to treatment and also target the tumour with a greater degree of specificity"

One gene Professor Darling is investigating is 'p53', which seems to sense and respond to the slightest damage caused to a person's DNA. It detects damaged cells and tries to fix them, but if they are beyond repair it leaves them to die. It does this by producing a protein that accumulates in the cell nucleus.

"With the protein accumulation", said John, "some cells become more sensitive to chemotherapy and the University of Wolverhampton is funding a PhD student, Sonia Guidi, to examine what mechanism causes this reaction. If we know how to manipulate the p53 gene it should make tumour cells more sensitive to chemotherapy and make treatment more effective".

Another of Professor Darling's areas of interest lies with a cell surface receptor present in a proportion of patients with glioblastoma. This is called the epidermal growth factor receptor (EGFR). In some patients, this growth factor has a piece missing and in some unknown way, this makes the tumour more aggressive and resistant to chemotherapy.

"We are developing new culture systems in the laboratories to increase this expression of the mutant form of EGFR so that we can test drugs which will bind to it and prevent it signalling."

Moving to the University of Wolverhampton has brought John Darling into close contact with other professionals and academics with whom he would never have thought to collaborate at his previous post and he believes that this multi-pronged attack on brain cancer is unique and could increase the chances of success.

He said: "Together with Dr John Howl and Dr Iain Nicholl, we are looking at trying to develop a targeting system to treat an important type of brain tumour in children, medulloblastoma, which can spread to cells on the spinal cord. It should just kill off malignant cells and we are hoping that within about five years, the system will be ready for clinical trials."

A further approach is not to attack the cells of a tumour directly, but the vessels supplying them with blood. Glioblastoma has abnormal blood vessels and if the supply could be interfered with and disrupted, the brain tumour would die. The Applied Sciences team hopes to use receptors present in the blood vessels to specifically target tumours in the brain without affecting normal tissue.

"I am dealing with people involved in other areas, such as immunology and pharmacology, who can all contribute in a very important way to this research. Another major advantage of being in Wolverhampton is that it is at the heart of the Black Country Cancer Research Network centred around New Cross Hospital where David Ferry has had great success in running large scale national clinical trials. It is a truly unique opportunity for me here".

With excellent facilities and a growing research base, the School is fast gaining a reputation for innovation and Professor Darling is actively approaching the major cancer research organisations to tap into funding streams.

He added: "My research has been helped in the past by the Samantha Dickson Research Trust (probably the largest supporter of laboratory based neuro-oncology in the country) and we hope to continue that relationship. The UK Brain Tumour Society has expressed an interest in funding research here and we have also approached the charity Ali's Dream regarding funding."

SDRT Spotlight

COMMUNITY FUND

An anti-depressant drug

called Clomipramine was shown in laboratory conditions to suppress tumour growth, and in some cases reduce the growth. Due to the delay in the start of the trials, the charity has helped 350 "anecdotal patients" on this treatment, and the majority have shown clinical improvement. However, it is early days yet and scientific evidence from the trials must be obtained to prove the efficacy of the drug.



Geoff Pilkington and SDRT SMAB board

Anyone interested in knowing more about the treatment should contact the SDRT, who are co-ordinating the trials for Professor Pilkington, on 01252 627426.

MATTERS

Delay in diagnosis by GPs

The SDRT also won a Community Fund (Lottery) Grant to tackle, “Delays in diagnosis of brain tumours in childhood”. This project will be carried out by Dr David Walker at the University of Nottingham. Many parents have suffered the consequences of delay in diagnosis, and this will hopefully establish National Guidance for GP’s, graduates, and under-graduates to recognise early symptoms. If earlier diagnosis is achieved it could improve survival rates, and reduce the problems associated with memory, concentration and thinking processes associated with late diagnosis.

Ali’s Dream

Just two years after the launch of the charity Ali’s Dream, which raises funds for research into childhood brain tumours, the trustees are delighted to announce their first research project is underway. An invitation for further funding applications will be issued early 2004.



Ali’s Dream Trustees with Sheila Hancock

The most common form of brain tumour found in children is a type known as astrocytoma. Although many of these tumours are found to be benign, approximately 20% will be malignant. The chances of long-term survival are poor, especially for astrocytomas of the pons where less than 10% of children are still alive two years from diagnosis.

Ali’s Dream is funding a research project led by Dr Tracy Warr (Institute of Neurology – University College London) costing £90,000 over three years.

Dr Warr’s project uses new gene microchip technology to determine which genes are inappropriately switched on in childhood astrocytoma brain tumours. The results of this study will enable scientists to exploit new treatments through a greater understanding of:

- **Which genes make cells grow, divide and multiply to increase the size of the tumour**
- **Which genes resist chemotherapy or radiotherapy, reducing the chances of arresting tumour growth**
- **Whether genes that stop cell division from occurring do not work in brain tumours**

Nikki Potter, a PhD student, started work on the project on 1 October 2003 and has been preparing samples to start the analysis, which started at the end of January. The first round of results should be available towards the end of 2004.

Gary and Julie Phelan say: “When Ali was diagnosed with a brain tumour, our whole world came crashing down. This was followed by

ten months of hell on earth. Since Ali’s Dream began, we have met with many highs and lows. The missing her gets stronger and the hole she has left gets deeper. We are being helped through this by our initial dream to make a difference. Funding our first research project is just one step along the way, thank you so much to those who have helped us and continue to help us in our Ali’s Dream.”

Gary & Julie Phelan, Ali’s Dream, 30 Hermitage Way Stanmore Middx
or Tel: 0208 863 6068

ANDREA’S GIFT

This research project is part funded by Andrea’s Gift.

Conditionally Replicating Adenoviruses and Brain Tumours

Viruses are microscopic particles that rely on infecting the cells of other

living organisms for their life cycle. When a virus infects a cell it alters a variety of cell functions and causes the cell to produce new virus particles. These are then released killing the cell in the process. Viruses convert cells into “virus factories” producing millions of daughter viruses per cell.

In order to achieve this cell conversion, viruses must disrupt cellular controls designed to allow orderly cell growth and division (cell cycle). These cell cycle control functions are performed by a group of proteins and, when disrupted, uncontrolled cell growth occurs. Uncontrolled cell growth is also a feature of cancer. The proteins disrupted by viruses also turn out to be absent in many cancers, including the majority of brain tumours.

The basis of our work is to culture tumour cells in the laboratory and expose the cultured cells to two conditionally replicating adenoviruses. These viruses target cells with different cell protein defects. Comparison is made with the wild type adenovirus (which is responsible for mild throat infections in humans) to determine how efficiently tumour cells are killed. We have now completed experiments on fourteen tumours. Twelve of these tumours have been killed by one of the test viruses to a degree equal to or better than the wild type virus. The second test virus has also proved effective in killing tumour cells, but to a lesser degree than the wild type virus.

These encouraging early results are being supplemented with further studies characterizing the protein abnormalities in the cultured tumour cells. We hope to increase the number of patients in the study as a prelude to possible future clinical trials if the results seen so far are reflected in the larger study.

I should like to acknowledge the generosity of all the patients who kindly agreed to take part in this study.

Greg Hall, Neurosurgical Research Fellow,
Department of Neurosurgery, Leeds greghall_icrf@mac.com



Some members of Andrea’s Gift’s trustees, taken at a presentation of a cheque to the charity

Putting the UK into UKBTS!



How you can help to realise our dream of providing local support right across the UK

Br-ring, Br-ring...Hello, UKBTS. Can I help you?

No, this is not the script for a new office sit-com or an advert for BT.

When the telephone rings in Jane Stephens's office it is often someone - like you or me - wanting help or advice about a brain tumour or another type of brain disease. Jane speaks quietly and calmly, promising to send out printed information. Jane may also arrange for someone - a UKBTS Helpline volunteer - like you or me - to contact the caller, offering support and the opportunity to talk. Having someone to talk to can be crucial for a patient or a carer in coping with brain disease, especially when the Helpline volunteer understands some of the problems, the pain, and stress caused by brain tumours.

It is increasingly clear that this very personal kind of support needs to be rolled out over the whole country. After all, there are fifteen NHS centres across the UK (as well as the private sector) which specialise in diagnosis and treatment of neurological diseases. As patients benefit from improved diagnostics and new treatments, and brain tumours are identified much earlier, the need for support grows. In order to meet this demand for information and support, we are aiming to strengthen and extend the UKBTS Support and Telephone Helpline. We want to provide more support on a regional basis so that people can meet up as well as talk to each other. We envisage the formation of regional forums to give support where people live, somewhere they can meet regularly.

To do this successfully we need your help. There may be a role for you as a member of our support team or as someone to get the ball rolling with local fund-raising activities. We also need volunteers to create an up-to-date register of all the brain charities and support groups in the country. This information, gathered and checked by volunteers, will be entered on a UKBTS database so we can match people up with established groups close to where they live. Obviously, you need to consider what may be required of you as a

volunteer. First of all, you need to have time to give; to feel comfortable handling 'phone calls. And you may need to attend a training day to develop the listening skills required to hear what others are saying, and to focus your attention on their situation rather than your own experience. In doing this we will be working together for the benefit of people coping with brain disease, and their families.

Over the past eighteen months volunteers have attended UKBTS Training Days to prepare themselves for the sensitive task of identifying what people want when they call: what information is needed, how to answer different questions, and how to empathize with people who may need to unburden difficult feelings. To do this we have drawn on the experience of CancerLink and Macmillan who have been providing support to cancer patients, their families, and carers for many years.

We do not set out to give medical advice or opinions; that is for the patient's doctors to do. But we can help explain the facts and clarify the medical jargon. For people facing treatment or choosing between treatment options, the chance to ask questions or talk to someone who has been through it, is reassuring. Good information and clear explanation can boost faltering self-confidence at a difficult time. Some of us may be looking for a little extra support when we are getting our personal and working lives back to normal after neurosurgery or radiotherapy.

If you would like to know how you can help with any aspect of UKBTS support work, or you can see what needs to be done in your region, then do please get in touch with me, Ella Pybus at meningiomaUK@aol.com. Tel: 01787 374 084 or Jane Stephens, jane.stephens@ukbts.org.uk. Tel: 0845 4500 386

Let us help you!

Get friends and family to sponsor you in anything you decide to do to raise money. To find out how easy it is to set up your own web page so you can raise money for a good cause while doing yourself good too, visit www.justgiving.com/charity/ukbts

Charity Flowers



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Just let them know that you want the profits on your order to go to UKBTS

To find out more visit their website, www.charityflowers.co.uk or write to POBox 555, Guernsey GY1 6JA for a brochure.

G I F T A I D

- Use Gift Aid and you can make your donation worth more.
- For every pound you give us, we get an extra 28 pence from the Inland Revenue.
- This means £10 becomes £12.80, and £25 turns into £32. Imagine what a difference that could make - and it doesn't cost you a thing!
- So, if you want your donation to go further, simply complete this form and send it, together with your cheque or postal order payable to UKBTS
- You can also donate online at www.justgiving.com/ukbts

I wish to help UKBTS in its work and enclose a cheque for £ _____

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THE UK BRAIN TUMOUR SOCIETY
Registered Charity Number 1068338