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This Newsletter...

If you have received this magazine in the post and we have shown your name and address details incorrectly, or you do not wish to receive future issues, please write, fax or email us at the Horley office. If you would like to be added to our mailing list, please let us know.

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UKBTS
THE UK BRAIN TUMOUR SOCIETY
Registered Charity Number 1068338

FROM THE CHAIR

As some of you will know, Zoe Hoppe has taken on the role of Chair of UKBTS, on a temporary basis until a permanent Chair is appointed.

Zoe, whose husband Angus, a highly respected Edinburgh GP, sadly died of a brain tumour in 1992, has considerable experience of working within the charitable sector. She has been a social work practitioner, a director and a volunteer, and has a passion to see UKBTS achieve its objectives. Zoe writes:

When patients, relatives and three registered charities joined together to form our charity in the Spring of 1997, the goals were clear:

- *To support those affected by brain tumours*
- *To raise awareness regarding the impact of this devastating condition*
- *To promote research into the cause, cure and prevention of the disease*

Two years on, we have many achievements to celebrate. The Millennium approaches and I am privileged to take on the chairmanship of UKBTS, albeit in a short-term capacity, at a most exciting time in its development.

My concurrent chairmanship of Brain Tumour Action (BTA), a 'sister' charity in Scotland, encourages a rich exchange of skills, knowledge and resources between the two organisations.

Creative links between UKBTS, BTA and other brain tumour charities, such as Brainwaves in Northern Ireland, will enable us to develop consistent and high quality services throughout the UK. It strengthens our cause.

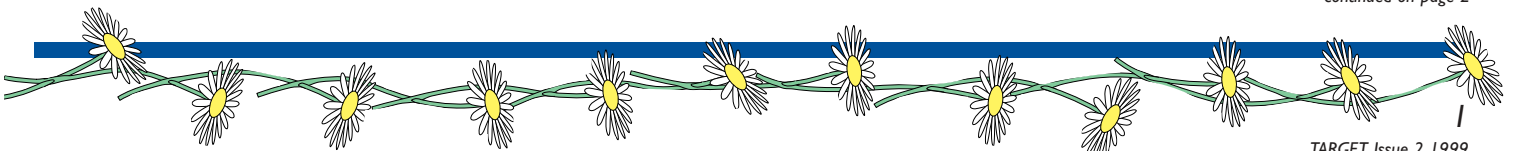
I am delighted to report on the activities of the past year.

We have appointed a Development Manager, on a short-term contract, to establish 'the way forward'. This has allowed us to support volunteer effort, increase credibility, raise awareness about brain tumours and the challenges it presents, extend our support services and submit two significant funding applications - to the Department of Health (£100,000)



and the National Lottery Charities Board (£200,000). The latter, if successful, will provide the opportunity to establish two new permanent posts, filled by a Development Manager and two part-time Volunteer & Services Managers. This will allow us to make huge strides forward together.

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1999 has also seen a range of partnership initiatives with sister charities. The most significant of these is the Autumn publication of a range of information leaflets in conjunction with BTA.

Work has also started on an exciting volunteer programme that will give interested people an opportunity to become involved in our work. As well as helping to make a difference to the lives of those affected by brain tumours, volunteers can gain experience, learn new skills, make new friends and, at the same time, have fun!

I am delighted to report on significant successes in the research field.

The Samantha Dickson Research Trust, one of our four member charities, is already funding four research projects, 'helping to find a cure for childhood brain tumours' to the tune of half a million pounds over three years. Two more projects will be under way by the end of 1999, adding a further quarter of a million to the total.

Further research projects are planned. Applications for the year 2000 will be reviewed by our Scientific & Medical Advisory Board in December 1999. UKBTS is in a position to fund one of these recommended projects, thanks mainly to the magnificent fund raising efforts of the Luke Frost Brain Tumour Research Fund.

These successes would not be possible without the hard work of our trustees, volunteers, Development Manager and to the committed leadership of my two predecessors, Neil Dickson and Keith Brueton.

I would like to thank them and those individuals and organisations who, through generous donations of money, prizes, time and energy, help us to 'shoot the arrow' — straight, sharply and steadfastly towards our Target.

Let us together hit the 'bull's-eye' again and again, and make an impact on this devastating disease!

Zoe Hoppe

Don Hart

It is with sadness that we have to report the withdrawal from UKBTS activities of Don Hart, for personal and health reasons.

Many of you will have come into contact with Don over the past two years in one or another of his capacities - trustee, befriender (and friend), fundraiser, newsletter editor, founder of Give Hope, minute-taker, photographer, to name but a few! His tireless efforts on behalf of the charity and its 'members' will be sorely missed. We wish him, June and Robert a happy and healthy future.

Roger Gould will be editing **TARGET** until a suitable editorial team can be found. If you're interested in helping - whatever your experience - please do let him know.



YOU are your newsletter!

We had lots of complimentary remarks about the launch issue of **TARGET**. Don Hart (see left), Nigel Boutwood and designer Graeme Jenner set a high standard that we must strive to maintain. We hope you enjoy this issue.

We did have one or two constructive criticisms - notably that, although UKBTS represents all age groups, the emphasis in the first issue of **TARGET** was heavily weighted towards children. We'll do our best to provide a fair balance in future issues but it's fair to say that most of the reportable news we receive does relate to children.

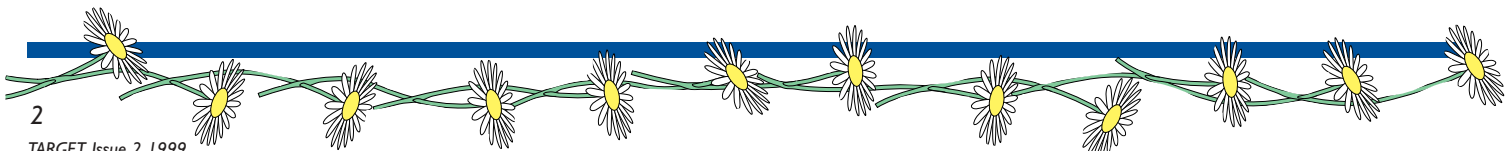
If you have something to say, let's hear it! It's your newsletter and without you it's nothing. Tell us what you'd like to see in it and what you're not so keen on.

Maybe you'd like to tell us about that fundraising idea you've been thinking about, your survivor's story, tips and advice for others affected by brain



tumours, or helpful books you've read.

Always bear in mind that some readers will be at an early point on their 'journey'. They may be reeling from a recent diagnosis and may not be able to face the stark realities that others have accepted. So, wherever possible, emphasise the positive, offer hope and encouragement, and try to avoid detailed medical issues.





Dr John Darling

A VIEW FROM THE LAB



Dr Geoffrey Pilkington

In response to readers' requests, Dr John Darling and Dr Geoffrey Pilkington, medical research scientists on the UK Brain Tumour Society Scientific & Medical Advisory Board, here give their view of the current state of play of UK-based brain tumour research.

The fundamental role the brain plays in defining the personality of an individual makes the diagnosis of brain cancer particularly frightening for patients and carers. Common questions for a family facing the diagnosis are 'Is there any research going on in this area? Are there any new therapies available in the UK or elsewhere which might be beneficial? Are there any breakthroughs on the horizon?'

Programmes of laboratory-based brain tumour research are being actively pursued in a small number of UK centres. There are research groups in Belfast, Birmingham, Cambridge, Edinburgh, Glasgow, Liverpool and London, and a handful of other workers carry out a modest level of similar research at other centres.

The range of laboratory research in the UK is, however, surprisingly wide. In London (King's College, KCL) and Belfast, research focuses on elucidating the biological mechanisms which underlie invasion of brain tumour cells into the normal brain and on selectively targeting these invading cells for novel therapies. Groups based in London (University College, UCL), Cambridge and Liverpool are involved primarily with achieving an understanding of the genetic basis of brain tumour development and, again in London (UCL), why these tumours are so resistant to therapy and how this resistance may be overcome. In Edinburgh, workers are attempting to understand why brain tumours are protected by the blood-brain barrier and, in Birmingham, new gene therapies and anti-sense therapies are being investigated.

Yet, in contrast to many other types of cancer and neurological diseases, this level of activity is rather low. Why is there so little brain tumour research in the UK? Partly because the treatment of brain tumours takes place in specialised clinical neuroscience centres, where resources - in terms of both medical experience and finance - are concentrated.

There is no doubt this is the optimal way to deliver high quality brain tumour treatment. However, there has not been a systematic attempt to match these multi-disciplinary clinical services with programmes of laboratory research which can be used to identify new therapies, evaluate them and then, in collaboration with the clinicians, bring them rapidly to the clinic. Similarly, contact with clinicians helps laboratory scientists appreciate the clinical problems these tumours present.

The second factor impeding progress is the lack of funding for neuro-oncology. It lies at the interface of clinical neuroscience and

cancer research and, as a result, has perhaps attracted less interest from both clinical communities.

More people are afflicted with and die from important neurological conditions like stroke and Parkinson's disease, or cancers such as those of the lung, breast or colon. However, brain cancer is probably the second biggest killer of children under the age of 16 and is a significant cause of death and disability in adults of middle age.

In the United Kingdom, about one in a hundred people who develop cancer develop it initially in the brain. This translates to about 2500 new patients every year. A much larger number of patients with cancer elsewhere in the body - like the lung, colon or skin - develop secondary tumours (metastases) in the brain. Viewed in this context, the level of funding available for brain cancer is surprisingly and disappointingly low.

Clearly this is unsatisfactory and steps should be taken to establish much larger research groups and encourage local interactions between basic scientists and clinical researchers, in order to optimise the path from laboratory to bedside.

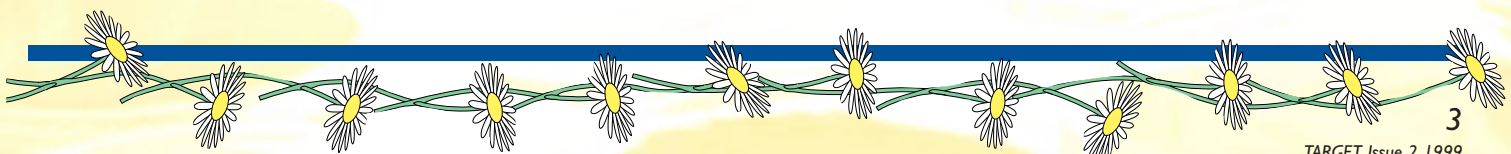
So much more could be done if only there were more funds available. There is no lack of ideas - simply the financial resources to exploit them.

What does the future hold? There is no doubt the biological information being amassed will tell us how these tumours develop, undergo malignant progression and resist current therapies. Armed with this knowledge, it should be possible to develop strategies to slow or halt tumour progression, make them more sensitive to therapy and identify sub-groups of patients who will benefit from particular forms of therapy. It should also be possible to develop entirely new types of therapy based on a sound understanding of the biological nature of these tumours.

It would not be unreasonable to anticipate that, over the next five to ten years, a range of biological molecules will be identified which can be targeted with new drugs and gene therapies.

Ironically, brain tumours are in many ways ideal tumours for which to develop new therapies. The brain is anatomically localised within a rigid box, the skull. This means sophisticated neuro-imaging techniques and surgical delivery systems can be used to deliver substances to very localised areas within the tumours, and any changes in tumour growth can be very accurately monitored. New, rationally based therapies developed for brain tumours may well eventually lead to improved therapies for patients with other types of cancer.

The authors are from the University of London. John Darling is based at the Institute of Neurology, University College and Geoff Pilkington at the Institute of Psychiatry, King's College.





FUNDRISING HIGHLIGHTS

In the first of a regular feature, Roger Gould highlights just a few of the many successful events that have taken place and the people behind them. Not only is this a way of our publicly thanking volunteers for their magnificent efforts, it also gives ideas to others looking to raise money for UKBTS.

Organising an event can be time consuming but it's fun to do. It's very rewarding and can represent a wonderful tribute to loved ones. It's also a brilliant way to meet other people and to get them involved. If you'd like more information about any of the events mentioned here, write to UKBTS head office and we'll forward your letters to the people involved.

Katrina Kuibida, from Leominster, near Hereford, whose 8 year old son **James** has a brain tumour, raised nearly £1800 from a 'marathon step' - a sponsored aerobics event.

18 year old **Michael Crow** from Bishop Auckland, although blinded by a brain tumour, completed his second Great North Walk. He raised £62, bringing the total he has donated to UKBTS to £173.

Class 8A at **Beaverwood School** in Chiselhurst, Kent, raised £12 by getting people to guess the number of sweets in a jar.

Sue and Andrew McLeod from Kendal, together with relatives, have raised over £2000 since the sad loss of their son **Benjamin**. Events included a Disco that brought in £1670 and Sue's sister-in-law **Christine Sturgiss** collecting £46 from a 'guess-the-unborn-grandchild's-weight' competition at her 50th birthday party.

Gill and Chris Wood held a Scalextric car-racing tournament in their garden in Bromley, Kent, in memory of their son **Matthew**. They raised £2800, half of which was donated to UKBTS (see story page 5).

Elizabeth Harries, from Teddington in Middlesex, collected £312 from a sponsored head shave.

Amy Ballantyne, aged 8 from Hereford, raised £207 from a sponsored one-mile swim. She was keen to do something after the sad loss of two friends - **Jake Merricks** (6) and **Lauren Redpath-Potter** (9) - she met at Birmingham Children's Hospital while her sister was a patient there.

As reported in the last issue of **TARGET**, **Don Hart** and other **Camberley firemen** collected £1200 from a car wash and gave £780 to UKBTS' Rapid Response Fund.

More than £5,600 has been raised in memory of **Angus Gibson**, including £2076 from a Talent Show at **The Portsmouth Grammar School** and £242 from a Carol Concert at **Glenhurst School** in Havant.

In Kings Lynn, in Norfolk, under-12's competed for '**The Ian Ferguson Memorial Trophy**' in a soccer competition organised by Ian's best friend **Kevin Hardy**. It raised £1026.

Family and friends of Lauren Redpath-Potter, who lived in Rugby, have so far raised nearly £1700. The local **North lands County Primary School & Nursery** made £213 from a 'healthy cake' stall and other activities, and two other schools - **Manor School** near Welling borough and **The City of London School for Girls**, gave £158 and £200 respectively. A sponsored walk brought in £500.

Linda and Gary Frost organised the Medstead Sports Extravaganza, otherwise known as the '**Luke Frost Games**' after their sports-mad son. The event raised more than £8000, and £5000 went to UKBTS research funds (see story page 6).

A dance organised by **Sue Whittred** her husband **Ernie** (a brain tumour patient) and friends in Attleborough, Norfolk, raised £475.

Through **Sam Ward**, a member of staff at The Institute of Neurology in London, the **3rd Welwyn Brownies** raised £125 for UKBTS at a 'bring and buy' stall.

Brain tumour patient **Lynne Omell** and daughter **Johanne**, from Sunninghill in Berkshire, held a garage sale and a car boot sale. The result was a donation of £1000 to UKBTS. This was on top of the £567 Lynne and friends made by charging for car parking during Ascot Week.

James Allen's Girls' School in Dulwich, south east London, raised £114, mainly from the sale of non-alcoholic cocktails.

The **family of Benjamin Edwards**, from Oswestry in Shropshire, have donated £861. £200 of this was from a quiz at his grandfather's local pub, **The Three Pigeons**, while Ben was still alive. The 11 year old read out the raffle numbers and presented the prizes.

Heartfelt thanks to all concerned and apologies if your event hasn't been included here. If you think your fundraising efforts merit a mention, why not write to us and tell us the 'who', 'what', 'how' and 'how much' of it all?

REV RUNS UP £££

For someone who doesn't regard himself as a runner, 60 year old Revd Terry Smith did rather well in the 1999 London Marathon. Not just by beating his personal time target, but for the magnificent sum he raised for childhood brain tumour research in the process.

Terry's inspiration was his friend Luke Frost, who tragically died of a brain tumour in August 1998, aged 10. Luke attended St Andrew's in Medstead, where Terry was the vicar until he moved to Oxford in July 1999.

Terry was moved by the efforts of Linda and Gary Frost and other parents to raise money to fight the disease. "I was humbled", he said. "They had all lost a child and they were working so energetically to prevent it happening to others".



And so, determined to do his bit to help, Terry applied for and secured a place in the 1999 Marathon. Months of gruelling road training, aching limbs and appeals for sponsorship followed. But all the effort eventually paid off, with Terry completing the 26-mile course in 5 hours 9 minutes and

handing over a total of £4711.70 to the UKBTS research fund.

UKBTS had another runner in the 1999 event. Brian Ashwood, from Wallington in Surrey, shared his sponsorship money amongst a number of charities, including UKBTS. Brian raised £772 for us and he tells us there's more to come.

Thanks Terry and Brian, not only for the money raised, but for the inspiration you've now given to others.

Both have applied to run on behalf of UKBTS in the 2000 Marathon, as have several others. We're planning to support them in a big way before and on the day - 16 April 2000 - so watch this space!

If you've applied for an individual place in the event and would like to run for UKBTS, or would like to help plan UKBTS' involvement, please contact Roger Gould via the Horley office.

THE MATT WOOD FESTIVAL OF SPEED

A novel fundraising event took place over the weekend of 4th and 5th September 1999. UKBTS was represented by Ron & Michele McConnachie and here they describe what went on.

This very successful event was organised by Gill and Chris Wood, in memory of their son Matt, and in aid of UKBTS and St. Christopher's Hospice, the local hospice Matt attended. 23 year old Matt sadly died in January 1999 from a recurrent brain tumour.

Matt was a keen motor racing enthusiast and worked as a veterinary nurse. His pride and joy Mini Cooper remains proudly gleaming in the front drive of the Wood's home.

The whole event took place in the family's back garden with a giant 'Scalextric' track built as a replica of an actual race circuit (one that Matt once said 'would make a superb Scalextric track!').

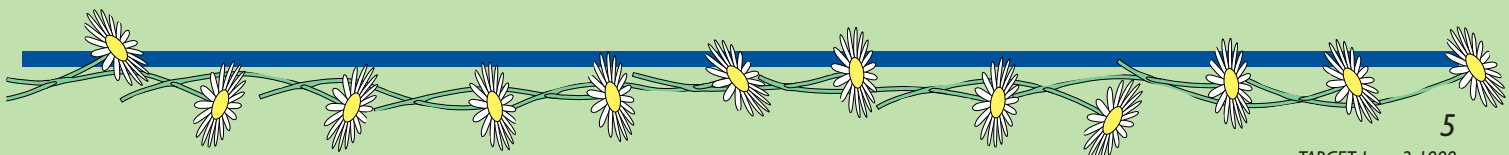
There were teams of four at £100 per team. The team members consisted of the many relatives and friends who had come to know Matt over the past years.

The weekend comprised race heats culminating in the Grand Prix race on the Sunday. This was a very serious event indeed, with practice laps to gain pole position and marshals strategically positioned to ensure fair play. The winning team members each received a commemorative 'Matt Wood Festival of Speed' T-shirt and their names were engraved on a beautiful trophy.

Despite the enormous amount of work and time involved, Gill said she intended to make it an annual event and the trophy had been prepared for that very purpose.

Hornby supplied the track at cost price, and cars and controls were donated free. Gill has offered to lend out the kit for other charity events.

A total of £2,800 was raised, shared equally between UKBTS and St. Christopher's. UKBTS thanks Gill and Chris for this wonderful donation - a fitting tribute to Matt. We look forward to next year's event, which is sure to attract even greater support.



RESEARCH NEWS

As previously reported in *TARGET*, UKBTS and member groups Samantha Dickson Research Trust (SDRT) and Charlie's Challenge each submitted a research funding application to the National Lottery Charities Board in October 1998.

We're delighted to say that SDRT's application - 'evaluation of the dietary additive aspartame ('Nutrasweet') as a risk for central nervous system tumours' - was successful.

The NLCB made an award of £147,624 towards the total of £187,074 for the three-year project, which immediately attracted headlines in the London Evening Standard and the national broadsheets.

The work, to be conducted by Dr Peter Nunn and Dr Geoff Pilkington of King's College, London, was due to commence in October 1999.

SDRT Chairman and past chair of UKBTS, Neil Dickson, said "We're delighted to receive this grant. It enables us to start our sixth

research project".

The award came only weeks after the charity commissioned its fifth project - investigating the genetic make-up of different types of childhood brain tumour - at Sheffield University Medical School.

SDRT's first research project, at the Royal Marsden in Surrey, was voted one of the top three cancer research projects of 1998, out of over 100 at the hospital. The project - 'Gene Therapy strategies for the enhancement of radiotherapy in human tumours' - is expected to proceed to clinical trials within two years. Successful trials could lead to a new drug treatment within four years.

Neil Dickson added "The tremendous support we've received - locally and nationally - means our hard work is really starting to pay dividends. Samantha would have been so proud".



Continued from Page 1

per cent increase in the incidence of brain tumours in the US during the early Eighties, and the growing use of aspartame. Their report looked at rats who were given a large amount of diet drinks and found to have more than four times the expected incidence of brain tumours.

However, the British Government's own Committee on Carcinogenicity decided at the time that there were flaws with the study, and that there were no grounds for re-opening an investigation. Experts had already looked at aspartame in 1982 and 1983, and concluded it was safe.

The new study is the result of £147,000 received by the Samantha Dickson Research Trust from the National Lotteries Charities Board.

Angela and Neil Dickson set up the trust following the death of their daughter Samantha so that funds could be targeted directly into clinical research.

Mr Dickson said today: "The work on aspartame is one of six areas which we are funding, after it was reviewed by the charity's 12-strong scientific advisory board and three international specialists. It is regarded as a valid area of clinical research and our mission is to improve the survival rates for those with brain cancer."

A spokeswoman for Nutrasweet AG, said today: "Aspartame's safety has been documented in more than 200 objective scientific studies which have been reviewed by authorities around the world. All of them have found it to be safe."

"It would be physiologically impossible for aspartame to cause brain tumours because it never enters the blood stream and cannot travel to essential organs such as the brain."

LUKE FROST

Those of you who saw the item in the launch issue of *TARGET* about Luke Frost and the research fund set up in his memory will be interested to read the following article from Luke's parents, Linda and Gary Frost.

Our fundraising efforts started in December 1997, eight months before Luke died, in a fairly small way, and we are so grateful to all those wonderful people who have supported us since then.

Of course, the Games, held in May 1999, were our major fund raiser of the year, bringing in £8,000. Over £5000 was passed to UKBTS and the rest was divided between local village organisations with which Luke was involved.

But in addition to this we've been touched by the willingness of companies and organisations to pass monies to our fund from their own events. S Grundon Ltd



Roger Gould receiving cheque for £5,000 from Linda and Gary Frost

have given us £1,158 from corporate and in-house Golf Days; ESA (The Environmental Services Agency) split half the proceeds of their Charity Ball in favour of The Luke Frost Fund - a marvellous boost of £2,255.

One organisation worthy of special mention is ILIACE - Independent Living in the Environment. They held a fun day for their residents - all of whom have very severe learning disabilities and a range of needs including epilepsy, autism and various

communication problems - and raised £911.

Some fine individuals too have raised sums. The Reverend Terry Smith ran the London Marathon and was sponsored for over £4,600. Jason Moore raised £700 for a sponsored parachute jump and Stuart Calloway £248 for a sponsored head shave. John Marlow was not only a key person in the Games organisation but also arranged a fun tennis afternoon, raising £319.

Add to this the overwhelming number of donations from other individuals and to date we have been able to pass a total of £28,000 to UKBTS. The money is earmarked for research into childhood brain tumours, hopefully towards a project on gene therapy.

Watch for news of the 2000 Luke Frost Games. UKBTS will be looking for teams to enter the tournament and mount a serious challenge for the trophy. It's an event to look forward to - immense fun, a great family day out and a wonderful way to raise big money!

WHAT IS A VOLUNTEER?

It's been said that a volunteer is a person who believes that people can make a difference - and is willing to prove it.

There's no doubting these words. You have to believe that, by giving your time and energy, you will actually improve the lives of others. Otherwise, why do it?

But there's so much more to volunteering - a word that conjures up stereotypes of middle-class, middle-aged ladies holding tea parties in aid of the local whatever.

Volunteering has moved on considerably over the past few years, with the realisation that volunteers - consciously or sub-consciously - do actually want and deserve something in return for their contribution.

It might be as simple as a word of thanks, being recognised and valued. It could be that they see it as an achievement, or as something from which they derive pleasure and pride, or as repayment of a 'debt'.

And, although they might not seek it, there are enormous benefits to be derived by the person volunteering.



Volunteers Gary Russell and Chloe McConnachie with model Sophie Dahl at the Cosmo Show

They could develop new academic, technical, advocacy, leadership and other skills - not just 'on the job' but through structured training, perhaps even leading to a new career. They might make new friends, find the work therapeutic, gain confidence, impart skills to others - the list is endless.

UKBTS is embarking on an exciting volunteer strategy that recognises the importance of the individual and provides the

rewards that make the whole activity worthwhile, effective and, above all, fun to do!

Although you may not realise it, each of you has a great deal to offer. It's just that you may not recognise how valuable your contribution might be.

Nor does it require inordinate amounts of time and effort to make a difference. A gentleman called Leo Buscaglia (who?) put it rather well: Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.

So, if you'd like to help us in our work - whatever, whenever, however much (or little), and whatever your age or circumstances - please don't hesitate. Just contact our Horley office and ask for a volunteer pack.

"You cannot do a kindness too soon because you never know how soon it will be too late."

Ralph Waldo Emerson

Easy as A, B, C

A new publication, The UKBTS A-Z of Fundraising Ideas, available from November, will be of interest not only to those new to the fundraising experience but also to seasoned campaigners.

The booklet contains a selection of ideas - initially one per letter of the alphabet (yes, X and Z included!) - with a brief description of what each involves and how to maximise the income from it.

The aim is to have more detailed information on each of the published ideas (written by UKBTS fundraisers) available on request, to expand the booklet with new ideas as they come to light and to reissue it on a regular basis.



So, if you've held a successful event - whatever it was and however small it may have been - please take a few minutes to send us the details (preferably on a

computer disk but don't worry if not).

Write it in your own words - the ups and the downs, from the initial concept to the post-event celebrations. We'll then produce it as an information sheet and send it to anyone who asks for further details of that type of event. We'll also add the idea to those in the booklet, if it's not already there.

If you'd like a copy of the booklet itself, please write to 'A-Z', UKBTS, BAC House, Bonehurst Road, Horley RH6 8QG, enclosing an A5 self-addressed envelope. It will help UKBTS to keep costs to a minimum if you can enclose a 31p stamp.



EMPOWERMENT TO THE PEOPLE!



Jenny Evans is 33 and has a low grade brain tumour. She works in the pharmaceutical industry as a market researcher. Here she explains how she thinks the brain tumour community can make an impact on the 'forgotten cancer'.

The brain is an organ of control. It is frustrating to be diagnosed with a brain or spinal tumour because there is a feeling that control has been taken away. It seems unfair. Not only does the sufferer have to cope with a potentially life threatening situation but the brain, the most important organ that is normally used for coping, is the very organ that has been affected.

This is why 'empowerment' is so important. Empowerment means 'getting some of the control back - and achieving what you want to achieve'. I have a brain tumour. Since my own diagnosis I have been studying community empowerment in connection with brain tumours. I believe that in order for us to achieve what we want to achieve we have to start operating as a community.

Let's assume that some of us would like a cure! A realistic assumption I think

It is essential for us to work more closely with doctors and scientists. *These people need to become part of our community.* In many cases they are as frustrated as we are. There is a serious lack of funding for brain tumour research and too few clinical trials are happening within the UK. Clinical trials are essential for testing out new treatments and for giving doctors a better idea of what is the best approach. Neurosurgeons, Neurologists and Radiotherapists have all said they need more resources and improved data in order to make better decisions on our behalf.

Some of the science gets 'left on the shelf' when it should be progressed into a treatment. This is because of the 'technology transfer' process. A variety of people are involved, including universities, and pharmaceutical and biotechnology companies. Our main hope is laboratory science and follow-on technologies - and there are some exciting new developments out there. We should try to understand this

process ourselves and, once again, bring these people into our community, so that we can work with them towards a cure.

There are lots of charities for lots of diseases. Fundraising is essential for extracting money out of the public. Conditions of the nervous system tend to fall behind things like heart disease and stroke when it comes to fundraising. The British Heart Foundation has about £40 million to spend per year on research, whereas the British Brain and Spine Foundation has about £400,000. Brain tumour charities in the UK also have very little money. Brain tumour specific fundraising is vital because there is not enough money to go around.

This is just the tip of the iceberg. There is a lot more detail to all of this. My project is for a Health Planning & Management Diploma. If anyone would like to discuss any of these issues, you are welcome to contact me. Write to me care of the UKBTS Horley office or e-mail me at:

evansj@bra.boehringer-ingelheim.com

THE Internet

In the last issue we introduced you to the Give Hope web site (<http://freespace.virgin.net/give.hope/>) and its many useful links to other brain tumour sites.

Here are a few more interesting brain tumour related sites (some of which are accessible as links from Give Hope):

Brain tumour resource handbook(Canada):

<http://www.btfc.org/english/handbooks/handbooks.htm>

Brain tumour clinical trials and much more (US):

<http://www.virtualtrials.com/>

Newcastle University:

<http://www.ncl.ac.uk/child-health/guides/clinks2a.htm>

We also briefly mentioned the discussion group, Braintmr. This is a free subscription facility, based in the USA, providing a forum for any issues related to brain tumours. More than 1000 people (patients, carers, professionals and interested others)

subscribe to the list, which has proved to be a lifeline for many.

It is probably the single most valuable brain tumour resource available. One word of warning though, you'll need to be fairly disciplined - subscribers can receive upwards of 50 messages a day. A useful introduction to the list can be found at: <http://www.braintrust.org/braintmr/braintmrguide.htm>

Please note: Although UKBTS is happy to recommend the Internet as a method of obtaining information and support, we cannot stress strongly enough that any information of a medical nature should always be discussed with your own medical team. Only they are in full possession of their patient's medical details. Any advice obtained via the Internet should be treated with caution.



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