



BRACE
Dementia Research

SPRING 2022
MAGAZINE

“I want to suggest that it’s time
for us to rethink dementia.”

Willy Gilder’s
self-portrait,
artist and former
journalist, more
on page 4

Together We Will Defeat Dementia

www.alzheimers-brace.org

Breakthrough in Alzheimer's Testing

The world's first early Alzheimer's test has been funded by BRACE and developed by Dr George Stothart and his team at the University of Bath.

The test involves participants looking at a series of flashing images on a computer whilst their brain waves are measured using an EEG cap.

Small, subtle changes in brain waves occur when a person remembers an image. These changes are then measured by the cap. The person taking the test doesn't need to understand the task or respond and they may not be aware of their memory response.

The cap is able to detect Alzheimer's before symptoms are noticeable enough to visit a doctor. Researchers hope that this test could help lower the age of diagnosis by up to five years and be done as a part of a routine visit to the GP.

Whilst many people may say they would not like to know if they were beginning to develop Alzheimer's there are many positives to being diagnosed earlier.

Research has shown the only way to reduce the risk of dementia, or slow down dementia once diagnosed, is through lifestyle choices. This may mean stopping smoking, regular exercise and wearing a hearing aid if needed.

An earlier Alzheimer's diagnosis also allows for individuals and families to start planning for practical issues,



Currently there are only very limited medicines to help reduce symptoms in the early stages - these medicines do not stop the disease from progressing.

Lead researcher and cognitive neuroscientist, Dr George Stothart of the Department of Psychology at the University of Bath explains:

"We are at an exciting stage and are testing the tool in earlier and earlier stages of Alzheimer's and expanding the type of brain function it can measure, to include language and visual processing. This will help us to not only understand Alzheimer's but also the many other less common forms of dementia."

"Ultimately the Holy Grail of a tool like this would be a dementia screening tool used in middle age for everyone, regardless of symptoms, in the same way we test for high blood pressure.

such as financial planning to pay for a care home and putting a Lasting Power of Attorney in place.

Dementia researchers are excited by the possibilities that this test will give them. By understanding how Alzheimer's develops several years before the symptoms are noticeable, there is a new opportunity to develop potential medicines to stop or slow down the damage Alzheimer's causes the brain.

Above: Dr George Stothart
Photo Credit (all 3 pics): Nic Delves-Broughton/
University of Bath/PA

We are a long way from that, and screening in the absence of effective intervention comes with its own moral considerations, but this is a step towards that goal."

The test is currently being tested by the NHS and is only available to patients at two clinics, one in Bristol and one in Bath.

If the results continue to be promising and reliable, it's very likely the test will be found in many settings - from hospitals to GP offices and even used in the family home.

A big thank you to our wonderful supporters who made this research possible through their generosity and, of course, to Dr George Stothart and his team for their unwavering commitment to this research and the development of the test.

Keeping Your Brain Healthy

Whilst there is no cure for Alzheimer's or other types of dementia, lifestyle choices have been found to keep the brain healthier for longer and slow down or reduce symptoms once diagnosed.

What's good for your heart is good for your brain. That means regular exercise to get your blood pumping, be it gardening, running, or a round of golf. A healthy diet filled with fresh produce and lots of fruit and vegetables will also protect your grey matter.

Everyone has their vices, which may be hard to give up such as alcohol or smoking. Cutting down still has some brain health benefits if quitting is out of the question.

Stay in touch with loved ones and keep socially active, whether that is chats on the phone, taking part in new hobbies or meeting family and friends. Willy Gilder talks about the importance of socialising in his article on page 4.

A less well-known way to look after the brain is through wearing hearing aids if needed. Research has shown that people with hearing loss, who wear hearing aids have faster reaction times and this is thought to help protect brain health. Being able to hear also helps to be fully engaged in social activities, reducing loneliness and isolation which also supports brain health.

If you are worried about your brain health or think you may be developing Alzheimer's or dementia, book an appointment with your GP to discuss your concerns.



Exclusive Artist Cards for Dementia Research

Willy Gilder is a retired journalist and active artist living with Alzheimer's in Edinburgh. He was a guest panelist in 2021's online Together 4 Dementia conference, where he shared his experience of living with dementia.

A person living with dementia is more than their disability, they are loved ones, friends, neighbours and individuals with hopes and dreams for the future just like everyone else.

"I want to suggest that it's time for us to rethink dementia. To consider what people with neurodegenerative illness can do, to concentrate more on the positive and less on the negative."

Yesterday, in the company of others with dementia I spent the morning learning to count in Gaelic, and the afternoon writing poetry. It's fair to say that a lot of tea was drunk, and scones consumed...and the sound of laughter echoed around the community centre. But this picture isn't, I think, what people generally consider when they think of dementia: they're more likely to picture folk in the high back vinyl chairs, eking out their days. They

might think more of people in the later stages of the disease, and not realise that many people with dementia can lead good and fulfilling lives, and take part in meaningful, therapeutic and fun activity.

In our group were people at different stages of disease. A few are now finding communication hard. One struggles to concentrate now, another has become largely mute. But others are busy picking out scrabble tiles as prompts for poems, or listening back to the song we wrote together a few days ago. There is a lot of mutual respect and understanding - we know that our diseases will progress and that the lively person we meet one week may have changed in a few months or year's time. No one gets criticised for what they can't do.

I love them all. I was diagnosed with early stage Alzheimer's Disease in April 2021, with atrophy in my parietal lobes. This means that my eyesight rather than my memory is affected. Diagnosis during lockdown was, frankly, terrifying. But when I started to meet others with similar conditions life became easier. Not least, because between us much



goes unsaid. Others have been through the trauma of diagnosis, of losing driving licences, of renegotiating work and family roles, of trying to come to terms with being a 'person living with dementia': together, we understand.

Life isn't fair. Cancer patients have Maggie's Centres and free advice and counselling - by comparison the support offered to people with degenerating brains is poor. We are too easily cast aside and forgotten. But now, I want to argue, it's time for things to change. We know that purposeful activity can work wonders in terms of slowing the progression of illness. We know that people with dementia are capable of great things, if offered the chance and opportunity. Between us we write plays, paint pictures, run training courses and enjoy sport. Please help us persuade the world to rethink dementia.

Internationally renowned artist, Sarah Boden, has kindly donated three beautiful artworks for BRACE to create packs of six Any Occasion cards, left blank inside to add your own personal message or greeting. The cards are just £4.95 a pack with 100% of proceeds going towards dementia research.

Sarah creates dynamic abstract landscapes in oil, mixed media, watercolour and ink which explore narratives gained from living overseas in Asia, Australia and Europe. Living back in the UK since 2017, her work focuses on raising the awareness of the fragility of our planet whilst exploring the differences and similarities between cultures and landscapes in the east and west.

Art therapy plays a key role in her work which includes teaching and workshops. Sarah knows first-hand how hard it is to find help for

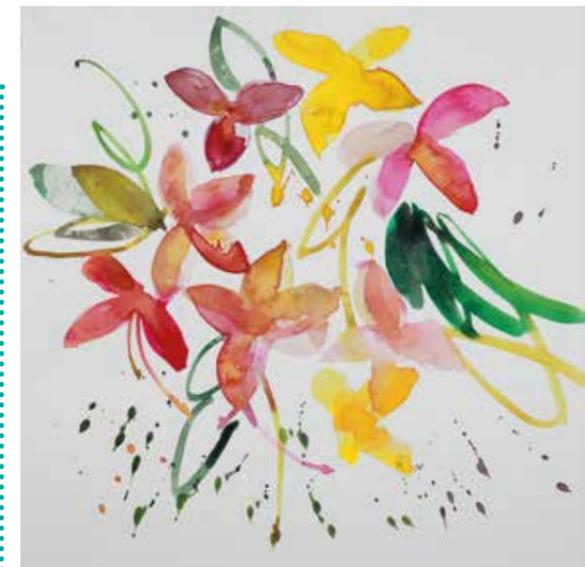
children and adults who are coping with learning issues or anxiety.

Sarah says, "I believe that art is such an incredible form of expression and relaxation and available to everyone. I hope that my work inspires you to start on a journey of your own and create authentic art which is personal to you!"

Sarah's many beautiful paintings are featured on her website. Please visit <https://sarahbodenart.com/> and Instagram/Facebook at SarahBodenArt



Size 140 mm x 140 mm



Artist Sarah Boden Card Order Form

Please return this form with your payment to: The BRACE Charity Office, The Brain Centre, Southmead Hospital, Bristol BS10 5NB

NAME (BLOCK CAPITALS PLEASE): _____

ADDRESS: _____

POST CODE: _____

TEL. NO (IN CASE OF QUERY): _____

| DESCRIPTION | PRICE | NO. OF PACKS | TOTAL PRICE £ p |
|--|-------|--------------|-------------------------------|
| Sarah Boden Greetings cards | £4.95 | | |
| POSTAGE & PACKING CHARGES | | | TOTAL CARDS: |
| UK (Royal Mail 2nd class) 1/2 packs - £1.40, 3/4 packs - £1.80, 5/6 packs - £2.50, 7/10 packs - £3.50. For 11+ packs please call 0117 414 4831 for quote | | | POSTAGE & PACKING: |
| For EU & rest of World rates, please email admin@alzheimers-brace.org with your order so we can calculate postage. | | | TOTAL AMOUNT: |

Cheque (made payable to BRACE) enclosed for £: _____

For payment by credit/debit card please give details below:

CARD NUMBER: _____

EXPIRY DATE: _____

SECURITY NUMBER: _____

SIGNATURE: _____

DATE: _____



Shobna Gulati, star of stage and screen and author of her moving memoirs, talks here about her experiences of life with a loved one living with dementia.

Remember me? Discovering My Mother as She Lost Her Memory



For families affected by dementia, this will feel like a familiar situation, one of a daughter caring for her mother in her time of need. Shobna's experience was bittersweet and allowed her to get to know parts of her mother's life and history which was previously unspoken.

Life became punctuated by rare but beautiful moments of tenderness between us, and moments of closeness that we had never experienced in our life together before. They would appear one day totally whole and beautifully painted, like a butterfly that only lives for a day. But they fluttered in and out of the house and made the tension, shame and loneliness all seem worth it. Even if they were only temporary, the sight and memory of them kept me going.

I introduced a different way of us being together after years of keeping our distance. Because of all her medication, Mum would often have headaches and I would massage her head and she just loved that. I'd run moisturizer into her legs and did as much touch therapy as I could. I would massage her back and shoulders, even through her clothes. That kind of physical intimacy hadn't been part of our lives, I would never have touched her like

that before, but I knew it was easing her discomfort and quietening her whirling mind. I'd sit up with her on her bed by the radiator and just be close, I even started kissing her forehead, she'd look at me as if to question it, but her eyes were full of the love and comfort it gave. Or sometimes she'd recognize that I might be tired, and would say, 'You can lie on my bed, beta, and take rest,' then plump up the cushions for me.

Every day was different, and every day would also have its hard moments. Sometimes, every single minute of the day was different. But you would still see glimmers of the woman I had lost in among the new woman who had begun to take her place, and the disquiet of the woman with dementia.

One day in September 2019 we were watching the news, and there was this story about a gold toilet that went missing from Blenheim Palace. That really tickled Mum. 'Was it the Queen's toilet?' she asked in fits of giggles? 'Where will the Queen go now her toilet is missing?' she said starting to silently shake. 'Shobna, do you think her wee is so special it can turn another toilet gold?' I burst out laughing at this farcical conversation. 'Loo larceny'

Life became punctuated by rare but beautiful moments of tenderness between us

was what she called it. And as soon as it happened it was over, and we were off somewhere else. She loved watching a repeat of *Top Gear, India*. Every time, she used to say the same thing, 'Who do these men think they are? They know nothing about India.' Even in her decline she could still get fiery about being patronized.

Even through all of this she refused to believe that she had dementia. If anyone mentioned the word in earshot, she would angrily snap, 'I haven't got that.' Even when I tried to explain, your heart is ill, your kidneys are not weak and your brain is poorly too, she would just not accept it. Sometimes she'd say, 'I don't know where my memory has gone to, I've forgotten what I was saying,' and she'd laugh over an anecdote she couldn't recall the details of.

There was a network of her mind that I didn't understand and nor did she

I stopped thinking about the future at all. I was too emmeshed in the duty of daily care and the world Mum now lived in, where her entire life was a great web we existed in, all hanging by a thread but in balance. There was a network of her mind that I didn't understand and nor did she, but it was connected, and although she

couldn't choose which parts of her memory she would be shown or when she would be transported to them and nor could I, we were there together in among them.

So, sat there side by side, cup of tea by cup of tea, breakfast, tablets, lunch, snack time, dinner, drink of water or no drink of water, loo visit by loo visit, from one moment of clarity to an angry outburst, to a near disaster to laughter which left us both silently shaking. Her recollections of her glamorous social life in stunning saris, arm in arm with my father, were now replaced by her memories of being a schoolgirl. We found intimacy in it all, as we rowed out together into the unknown of her illness, never knowing what wave could crash into us next. But for now, we had one another, and we had those butterfly moments too. I just lived one wave at a time, one problem at a time, one small triumph at a time, one meal at a time, and sometimes I found myself quite lulled by the dependability of the routine and other times shocked by what the next day presented to me.

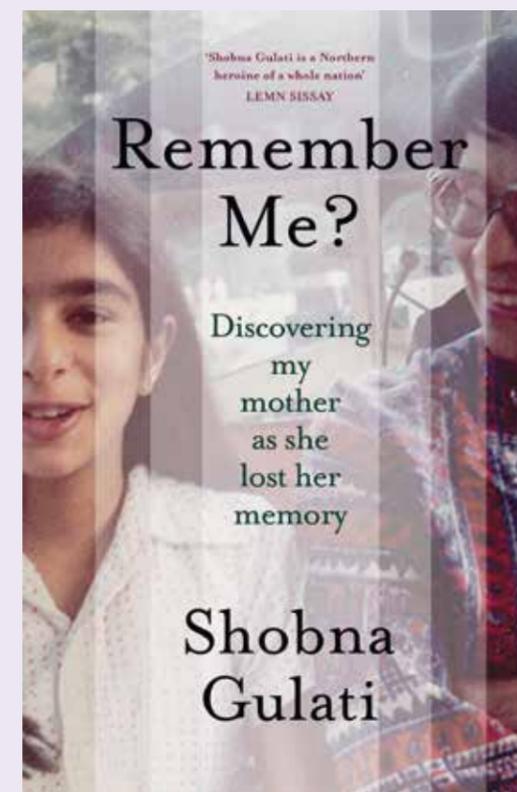
I just lived one wave at a time, one problem at a time, one small triumph at a time, one meal at a time

Sushma said to me, 'Let's get Mum to 80.' And because, like a cat, she had nine lives- a stroke, a heart bypass, congestive heart disease, bowel cancer, dementia - it didn't seem implausible. I didn't see any end. I suppose I didn't want to see the either. Despite all the rocks and the rapids, we were there together.

We just kept rowing out.



Thank you to Shobna Gulati and her team for giving permission for this extract to be printed free of charge. If you would like to purchase her book it is available in all good bookshops including, Waterstones, Foyles, Blackwells, Amazon, WHSmith and Bookshop.org



BRACE LOTTERY

You've got to be in it - to win it!
Sign up to the BRACE lottery to be in with a winning chance and help support dementia research at the same time.

Over the last 5 years the lottery has raised an incredible £43K for BRACE. If you'd like to take part, at just £1.00 per week per number, **please fill in the form below and send it to us at the BRACE Charity office, Brain Centre, Southmead Hospital, Bristol BS10 5NB.**

Alternatively, click on the link on our website to sign up online:
<https://www.alzheimers-brace.org/brace-lottery/>

Numbers are chosen weekly, using a random number generator. The more players the bigger the individual prize and the more money raised for BRACE! You can also have as many numbers as you like... Winners receive 25% of the prize fund with the remaining 75% funding world class dementia research.

Here are the results for the last quarter:

| Date of Draw | Winning Number | Amount Won | No of Players |
|--------------|----------------|------------|---------------|
| 3.11.21 | 31 | £51.50 | 206 |
| 10.11.21 | 29 | £51.50 | 206 |
| 17.11.21 | 27 | £51.50 | 206 |
| 24.11.21 | 26 | £51.50 | 206 |
| 1.12.21 | 54 | £51.25 | 205 |
| 8.12.21 | 58 | £51.25 | 205 |
| 15.12.21 | 239 | £51.25 | 205 |
| 22.12.21 | 35 | £51.25 | 205 |
| 29.12.21 | 138 | £51.25 | 205 |
| 5.1.22 | 149 | £51.25 | 205 |
| 12.1.22 | 111 | £51.25 | 205 |
| 19.1.22 | 59 | £51.25 | 205 |
| 26.1.22 | 163 | £51.25 | 205 |

The BRACE Dementia Research Lottery

NAME (BLOCK CAPITALS PLEASE): _____

ADDRESS: _____

POST CODE: _____

TEL. NO (IN CASE OF QUERY): _____

PLEASE COMPLETE

1 weekly entry (£4.34 per month) 2 weekly entries (£8.68 per month) If you'd like to enter more than 2 entries per week (£4.34 each) please circle the amount here: 3 4 5 6 7 8

SIGNATURE _____

DATE _____

Instructions to your BANK or BUILDING SOCIETY to pay by standing order:

Please pay BRACE £ _____ from my account of the 1st of each month until further notice

Please make the first payment on 0 1

ACCOUNT HOLDER'S NAME AS IT APPEARS ON BANK STATEMENT _____

ACCOUNT NUMBER: SORT CODE:

BANK NAME _____

BANK ADDRESS _____

POSTCODE _____

Instruction to your Bank or Building Society:
Please pay to National Westminster Bank Plc
PO Box 11, 12 High Street, Westbury-on-Trym, Bristol BS9 3BZ
Sort code 60-23-23
Crediting BRACE account 85058629
(Please quote reference Z plus the name of the originator)
Note this standing order should not be combined with/or have the effect of cancelling any other payment to BRACE.

CHANGES on board

BRACE owes a great debt to all its volunteers and this includes the Trustees. In a charity like ours, members of the Board are unpaid but give their time and take ultimate responsibility for all we do. We really cannot thank the trustees, both past and present, enough for their dedication and commitment to the charity and dementia research.

Since the pandemic started, we have seen five retirements and welcomed five new Trustees. We are grateful for the immense contributions of Peter Lippett, Kate Clarke, Stephen Lisney, Heledd Wyn and Sylvia Perry who have all retired since November 2020.

In their place, we have welcomed the breadth of knowledge and experience represented by Dr John Pounsford (clinician), Helen Bidwell-Ford (HR professional), Dr Gary Christopher (gerontologist), Chris Wilkin (physiotherapist) and Jonathan Williams (accountant).



Photo: Former Trustee, Sylvia helping at a BRACE event

We would like to include a special 'thank you' to Sylvia Perry, who retired in December after completing twelve years as a Trustee. She has been a supporter for much, much longer and continues in that role at fundraising events.



Remembering Mary Goronwy MBE

Mary, who died at the age of 82 late last year, was one of the volunteers who helped create BRACE in the 1980s and put her heart and soul in to the charity. She was a stalwart supporter for many years and an important link between the charity and her local community, notably with St Peter's church, Henleaze.

Thank you, Mary, for all you did to support BRACE.

Competition Time

GIRL'S NAMES

Fill in the missing letters to test your knowledge of the Top 25 most popular girl's names in the UK (2021)

- | | | |
|-------------------|--------------------|----------------------|
| 1 O _ i _ i _ | 9 _ i _ y | 17 _ o _ p _ |
| 2 A _ e _ i _ | 10 F _ e _ a | 18 C _ a _ l _ t _ e |
| 3 _ s _ a | 11 E _ i _ y | 19 W _ l _ o _ |
| 4 A _ a | 12 l _ y | 20 E _ e _ y _ |
| 5 _ i _ | 13 _ l _ a | 21 _ l _ i _ |
| 6 l _ a _ e _ l _ | 14 R _ s _ e | 22 P _ o _ b _ |
| 7 _ o _ h _ a | 15 _ v _ e | 23 _ o _ h _ e |
| 8 G _ a _ e | 16 F _ o _ e _ c _ | 24 S _ e _ n _ |
| | | 25 A _ i _ e |

Entry is £5.00 - closing date is Tuesday 31 May 2022

Please send your answers together with a cheque for £5.00 payable to BRACE to:

The BRACE Charity Office,
The Brain Centre,
Southmead Hospital,
Bristol BS10 5NB.

The winner will be contacted within 2 weeks of the competition closing and the winner's details will be announced in the next magazine. The answers will also be published.

The winning entry will receive a £30 gift voucher of their choice. The editor's decision is final.

Thank you for your support!

NAME: _____

ADDRESS: _____

POST CODE: _____

CONTACT NUMBER(S): _____

ANSWERS FROM THE SEPTEMBER COMPETITION (TREES) WERE:

1. Douglas Fir 2. Crab apple 3. Juniper 4. Alder 5. Willow 6. Cedar 7. Hazel 8. Copper Beech 9. Norway Spruce 10. Horse Chestnut 11. Scots Pine 12. Sweet Chestnut 13. Yew 14. Common Line 15. Silver Birch 16. English Elm 17. Holly 18. Sycamore 19. Blackthorn 20. English Oak 21. Hawthorn 22. Apple 23. Common Beech 24. Walnut 25. Eucalyptus

The winner lives in Portishead, North Somerset and chose a £30 Marks & Spencer voucher as their prize.

If you receive this Magazine by post or email, it is because we have you on record as having opted in to our mailing list. If you do not wish to receive our mailings in future, just send us an email or a letter and we will ensure that you do not receive further mailings.

List of Events

Please visit www.alzheimers-brace.org/events for more information and to sign up to challenge events.

| MAY 2022 | |
|-----------------------------------|---|
| Monday 16 May - Sunday 22 May | Dementia Action Week |
| Thursday 19 May 10 am - 11.30 pm | Alive Activities and BRACE - Gardening and Dementia Online event |
| Thursday 19 May 1.30 pm - 3.30 pm | Alive Activities and BRACE - Gardening and Dementia - Cuppa for a Cure at the Alive allotment, Charlton Road allotments, Brentry, Bristol, BS10 6XJ |
| Sunday 29 May 11 am - 3 pm | Bath Half Marathon 2022 Great Pultney Street, Bath |
| JULY 2022 | |
| Friday 1 July 7 pm - 11.30 pm | Summer Charity Dinner and Auction at the Bristol Marriott Royal hotel, College Green, Bristol, BS1 5TA |
| OCTOBER 2022 | |
| Sunday 2 October 9.30 am - 4 pm | London Marathon 2022 |
| NOVEMBER 2022 | |
| Tuesday 1 November all day 2022 | Together 4 Dementia Hybrid conference 'in person' We the Curious, 1 Millenium Square, Anchor Road |

BRACE is thrilled to announce it has been nominated by two brilliant businesses as their Charity of the Year for 2022

The Bristol Film Festival



& Hayes Parsons



We look forward to supporting them in their fundraising which we hope will be fun.

Enjoy a fabulous night out this summer at our



Charity Dinner & Auction



at the Bristol Marriott Royal hotel, on Friday 1st July, 7pm-11.30pm In aid of dementia research.

BBC Points West's Alex Lovell is host for the night and you will enjoy a delicious 3-course dinner, wine, music from a Jazz Quartet, an auction run by professional auctioneer Andrew Morgan and talented photographer, Simon Camper, will be there to capture the fun.

A chance to let your hair down and enjoy much needed time with clients, colleagues or friends in wonderful surroundings.

Ten tables of 10 are available at a cost of £550 and include dinner, wine and entertainment.

Individual tickets are £55 per person and can be booked by emailing Amanda Cole on: amanda@alzheimers-brace.org or calling Amanda on 07557 194 236



Paris in the springtime is usually a time to relax and stroll along the Champs Elysees you may think, but not for supporter Lizzie Anthony from Harrogate who decided to take part in the Paris half marathon on Sunday 6th March. And raised a whopping £740 for BRACE, finishing in 1 hour 56 minutes.

Lizzie decided to support us and the work that we do in honour of her grandma who sadly lived with Alzheimer's for the last 5 years of her life. She said "It's very warming to know the donations will be going to such a brilliant cause. I'm so glad I can contribute to this."

We're very glad that you chose us to support and I'm sure your grandma would have been very proud of your wonderful achievement 🏆



Bath Half 2022

Sunday 29th May
11 am - 3 pm

Keen runners wanted!

Apply for your **FREE** race place on the BRACE website



BRACE Donation and Contact Form

Please find enclosed a donation of £_____ to BRACE.

Thank you for your donation. Please tick this box if you do **NOT** want a written acknowledgement

- Please add me to your mailing list
 Please send me the magazine by email only

Please provide your contact details below so we can thank you or in case of query. If you are eligible to add Gift Aid, please also tick the Gift Aid box.

My Details

TITLE _____ FIRST NAME OR INITIAL(S) _____

SURNAME _____

FULL HOME ADDRESS _____

POSTCODE _____ DATE _____

If you would like us to phone or email you, please supply:

DAYTIME TEL NO _____

AND/OR EMAIL _____

Boost your donation by 25p of Gift Aid for every £1 you donate

giftaid it

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. **Your address is needed to identify you as a current UK taxpayer.**

In order to Gift Aid your donation you must tick the box below:

I want to Gift Aid my donation of £_____ and any donations I make in the future or have made in the past 4 years to BRACE

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Please notify the charity if you:

- want to cancel this declaration
- change your name or home address
- no longer pay sufficient tax on your income and/or capital gains

If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

We will keep a record of your donation/enquiry but will not contact you unless you have agreed that we can.

RETURN TO: The BRACE Charity Office, Southmead Hospital, Bristol, BS10 5NB.

Telephone 0117 414 4831

Registered Charity 297965