



The Brittle Bone Society

NEWSLETTER

Issue No. 99 — Autumn/Winter 2010

Supporting people who
live with bones that break

CONFERENCE SUCCESS!

New Project Volunteers and big targets set for 2011

I am so pleased with the outcome of the recent BBS AGM and Conference held in September at the Burleigh Court Hotel in Loughborough. The venue seemed to be a great hit with all the members who attended. We had superb speakers including Professor Nick Bishop who spoke to a packed pre-conference audience on the Friday evening, and were honoured that our proceedings were formally opened by the local Mayor Councillor Jill Vincent, who gave a heart-warming welcome to everyone from the Brittle Bone Society.

We covered topics that we hope you found useful and of interest and I was happy to get the chance to report back on the work I have undertaken on your behalf for the last 12 months. Our Fundraising Officer Christine Hope gave a well-received presentation with amazing, winning examples from you, our membership on how we raise much needed funds, and we closed Conference striving for great steps forward in 2011.

With an over arching emphasis on reaching high financial targets, growing our membership, increasing our lobbying powers and formation of a new medical advisory board, I need you to step forward and help us reach those goals. So please do what you can!

Our Trustees are already working on our new strategy to compliment all we have achieved in the previous strategic plan – and there was great excitement and willingness for everybody to play a part in helping our small charity realise our ambitions to grow.

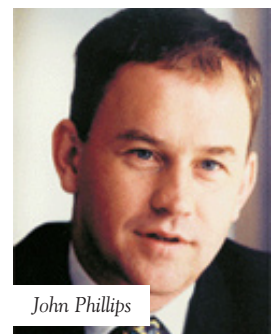
Christine Hope made an appeal to recruit more project volunteers to help us reach our new target of around £500,000 through fundraising. At Conference we were pleased to welcome Trisha Mckeown, who gave a presentation. Trisha revealed to the audience in simple steps, how she pulled off a successful Dinner Dance and auction in May which raised £5000 and how simple it was to raise cash for the BBS. Since then we've received contact from many members and friends who are keen to start work. For ideas on the types of events you can contact Christine who will give you as much help as you require to make your event a big success.



Toni Potterton Vice Chair, The Mayor of Charnwood Councillor Jill Vincent, Elaine Healey Chairman and Patricia Osborne CEO

NEW TRUSTEES

I said before, I promised you change and this year's Conference didn't disappoint. We worked through a packed agenda of events and workshops and it will be hard to improve on this year's event but we are determined to keep the momentum. I'm especially excited about our plans to extend our reach into Ireland. I am pleased to welcome back some Trustees who were re-elected and offer a warm welcome to our new board members – Mr Robert Gordon our new Treasurer and new Trustee Mr John Phillips to help us build on the work we have achieved to date.



John Phillips



Elaine Healey and Robert Gordon

30s-50s EVENT

We have had some suggestions from members who would like an event for those with OI aged 30-50, following our successful pilot Youth Event – VOICE earlier this year. We are looking to hold a half day meeting in the London area and at this stage would like to gauge possible interest in order to take the plans to the next stage. If this is something you would be interested in supporting/attending please contact our Support Worker Jill Murdoch.

CHARITY BOXING EVENT

Friday 22 October at the famous York Hall in London, we held a charity auction. We were invited to take part in this by our newest Trustee Mr John Phillips. It's the first time we have tried this type of event – and we were knocked out by the response. We raised almost £1700 and most of the gifts were donated. Amongst the fabulous gifts included an Arsenal Football signed by the squad which fetched £350, so thanks to the Emirates Stadium for this kind gift.



Left to right, John Phillips, Tom Lullaby McKay and Elaine Healey



Paul Oice and Patricia

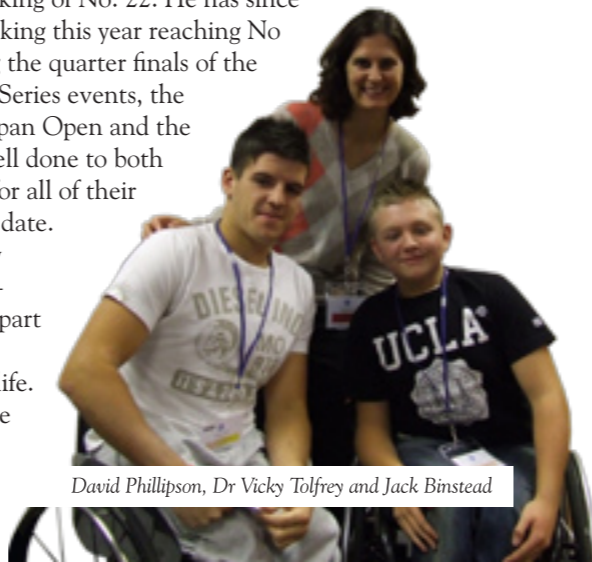


LONDON MARATHON APRIL 2011

We are delighted to let you know that we have three very enthusiastic runners taking part in the London Marathon for "Team BBS". Matthew Bowell, Lee Ford, and Abigail Player are all being kept very busy with a strenuous training programme as well as lots of fundraising. We are very proud to have them as our first ever Team BBS. Look out for further updates on our website.

SPORTING ACHIEVEMENTS

Young BBS members Jack Binstead and David Phillipson are flying high in their sporting fields. Both kindly agreed to talk at this year's conference alongside Dr Vicky Tolfrey, Director of the Peter Harrison Centre for Disability Sports at Loughborough University and were an inspiration to all. Earlier this year Jack won the Mini London Marathon for his age group and has continued to beat all of his track times during the many rounds of track events he has taken part in up and down the country. Jack won two silver medals at the year's London Youth games and has been accepted as a young ambassador to promote the London Olympics and Paralympics for 2010. David Phillipson first discovered wheelchair tennis at the age of 10 and 11 years later he is British No 1! In 2009 David reached the finals of singles events and won doubles titles in both Britain and the USA and ended the year with world singles ranking of No. 22. He has since improved his ranking this year reaching No 12 after reaching the quarter finals of the first three Super Series events, the Florida Open, Japan Open and the British Open. Well done to both Jack and David for all of their achievements to date. Jack's philosophy in life says it all – "Brittle Bones is part of my life, Brittle Bones is not my life. We only have one life, live it!"



David Phillipson, Dr Vicky Tolfrey and Jack Binstead

CONFERENCE AWARDS

At this year's Conference we had our first Awards and Recognition Ceremony. Each winner was presented with our new Wishbone Pin along with an achievement certificate. Please let us know if we should include other categories and tell us whom you would like to nominate for next year.

THE BBS FAMILY AFFAIR AWARD FOR 2009/10

This is to recognise the efforts of those who support us from right across the generations, from coffee mornings, discos, tea and cake stalls, family celebrations and more.

Winner: Andrew & Sara Marshall and family



THE BBS YOUNG AMBASSADOR OF THE YEAR AWARD

This acknowledges the efforts of one of our young members, who has consistently represented our society in public, with the media and beyond, and who is a shining example for all our young members.

Winner: Jack Binstead



THE BBS GROUP AWARD FOR 2009/10

Although we know there are many groups who have supported us for years, we want to introduce this to recognise the combined efforts of many individuals who come together in clubs and groups to help our causes.

Winner: Tenterden Golf Club



THE BBS INSPIRATIONAL AND INNOVATIVE CAMPAIGN 2009/10

The prize this year is for the event which generated the most interest and support amongst members across the UK.

Winner: The Wildcubs



THE BBS FINANCIAL EXCELLENCE AWARD 2009/10

A worthy prize to the individual or group who contributed the most funds towards the charity from one event.

Winner: Amy Shemilt



THE BBS EXTREME CHALLENGE AWARD 2009/10

An award to the most physical, stretching and demanding challenge undertaken on behalf of the BBS.

Winner: Naomi Dandridge



THE BBS LONG SERVING / LIFETIME ACHIEVEMENT AWARD 2009/10

This prize is especially for a group or individual who has consistently fundraised to help our Charity over a lengthy time period.

Winner: John & Gertie Farmery



BBS FUNDRAISING



Tasha Shackell, James Drinkwater and members of Wokingham Health Club, Curves did a sponsored walk



Christine Hope with Tayport Belly Dancers

I DID IT – WHAT A FEELING

By Rob Winstanley

On the 21st August 2010 my biggest challenge ever was achieved surrounded by my family and friends without whom this would not have been possible. The rain stayed away and the views were breathtaking. I battled through the pain and took every step aided only by my walking poles. At the hardest steepest points and when the pain was constant and getting to be unbearable, I remembered all those past fractures and being stuck in bed on traction, no visitors and no way out, that truly made me go on because I could. The last step that placed me at the summit left me with a feeling that words cannot describe and I felt free, alive and it was wonderful to do something I'd always wanted to. Don't let your disability rule your life, you live and do something that makes you smile at least once a day. The best thing to hold onto in life is each other and at the top of the mountain I held on to the people that mean everything to me. I would like to thank my family and friends for supporting me on the day and making me feel like the luckiest and richest person alive and to everyone who has sponsored me and given me words of encouragement a big, big thank you to you all. For those of you reading this from a hospital bed, I've been there done it got the t-shirt. Don't give up life gets better.



Rob Winstanley at the top of Dodd Summit

THANKS FOR ALL YOUR SUPPORT

Our thanks go out to everyone for their kind donations to the Brittle Bone Society. Here are a few examples of those who have fundraised in the past few months: Thanks to the Wildcubs who raised £5810.27 from their motorcycle trip around Scotland. The Dragon Clay Club continue to support the BBS giving a further donation of £1000 in September of this year. Curves in Wokingham have raised a massive £5028. The Marshall family coffee morning raised over £500. Runners in the Bristol half marathon raised welcome funds – Mark Kane £596 and Sword Apak team £394. Thank you to Heather Harman for holding car boot sales and raising £500. Daniella and Raven took part in a sponsored swim and made £1239. Yorkshire Building Society Charitable Foundation donated £100. BBS Trustee Yvonne Grant raised £251.11 from the sale of raffle tickets for the annual grand raffle. Catherine Belford received donations for the BBS in place of birthday presents for her 50th and raised £400. Toni & Catherine Potterton and friends raised £350 from a can collection at Tesco's in Bournemouth. The Griffith family challenge raised a huge £2423. And can collections at Tesco and Sainsburys in Dundee raised a total of £1635.

If you need any help with your fundraising plans for the coming months please get in touch.

TAKE PART AND RAISE MONEY

Challenge Scotland

Edinburgh, Sunday 6th December 2010 and Sunday 5th June 2011. Whether you would like to walk 1, 2, 3, 6 or 12 miles or run 5K all through the beautiful city of Edinburgh, this is the event for you. Please contact Christine if you would like to take part or register on line at www.challengescotland.com

The British 10k London Run

Ever wondered about taking part in a 10k race? This is the race for you! Join the successful BBS 10k Team which will for the 4th year be running around the sights of London. We have 18 places for the July 2011 event which will take place on Sunday 10th July 2011. Contact Christine as places are getting snapped up fast.

STAMPS, COINS & CARDS

Did you know you can help us raise funds by donating old coins, any kind of stamps and postcards? We can take notes, coins, stamps and postcards of any kind from any country. John and Mildred Price have been collecting and selling stamps, to raise funds for the BBS, for many years. You can send items directly to Mr & Mrs Price, 57 Mount Pleasant, Swansea, SA1 6EQ. Please ensure you put the correct postage on your parcel!

ERIC BOOTH

Engineer and Innovator in Wheelchair Design

Eric's first contact with the BBS was a phone call from Mr Sid Ashton in the early 1970's who called to enquire if Eric could make an elevating seat wheelchair for his daughter Beverly.

Eric set about putting together a rough design and passed to Research Technician Ken Sheppard. Ken then went on to build a chair with an 18" lift. This design went on to include a powered reclining backrest which was further enhanced and built by Chris Chinery who operates as the company Wireline.

Eric joined Queen Mary College (University of London) as a research fellow and manager of the design lab under Prof. M W Thring in 1970. Prof Thring was interested in the contribution that engineering could make to benefit people who were disabled. This went on to contact with REMAP and led to the formation of the Oxford and Thames Valley Panel being formed in 1977. Other innovations included the COMET designed by Ken Sheppard – a small battery powered children's mobility aid. (COMET – Child Operated Mobile Electronic Transport). There were obstacles to be overcome with the prototype like limited obstacle mounting ability although manoeuvrability was excellent. Eric then went on to design a new motorised base with 4 castors and 2 drive wheels using the 'tilting beam' principle, this proved to have reasonable obstacle mounting ability and the system went to patent in 1975.

Eric and his colleagues realised early on that their interest in mobility for disabled people would benefit from strong links with the medical profession, and in 1972 began co-operating with Occupational Therapists including Alison Wisbeach at the Wolfson Centre and they set about covering much of the UK.

COMETS are still produced by Wireline – a one man unit who has worked with Eric for around 20 years.

Eric is now 86 years young and still keeps in touch with members from the Society. The Brittle Bone Society fully acknowledges the early and vital innovations that Eric was involved with. Without Eric's early work, the designs of today would not have been possible. Eric's designs helped improve the quality mobility for many BBS members and we are pleased to get this chance to showcase his involvement and contribution. The charity still regularly receives royalty payments kindly referred by Eric for the work we do in assisting member's applications for his specific wheelchair designed equipment.



Amy Shemilt using her COMET



Eric Booth

BBSArts

Josie Griffiths, Adrianna Bertola, Kerry Ingram at Roald Dahl's house



A SHAKESPEARE STORY

Young BBS member Kerry Ingram (aged 11) has landed the lead role in the Royal Shakespeare Company's *Matilda, A Musical*. Kerry is sharing the role with two other young actors shown, so if you want to see Kerry in the play, please check with the theatre which nights she is performing. The production will be directed by Tony Award winning Mathew Warchus, the book is by playwright and screen-writer Dennis Kelly and the music and lyrics are by Australian comedian, musician and composer Tim Minchin. Kerry currently trains at Songtime Theatre Arts in Bracknell and has been in such productions as *Annie*, *The Wizard of Oz* and *Beauty & the Beast* at The Theatre Royal Windsor, and more recently in *Oliver!* at the Theatre Royal Drury Lane.

Matilda, A Musical is running from 9th November 2010 to 30th January 2011 at The Courtyard Theatre, Stratford-upon-Avon. For more information and tickets visit www.matildamusical.com or call 0844 800 1110.

BREAK A LEG

By Mark Ross, Trustee

They say dreams can come true and this one certainly did. After a 3 and half year wait I was finally given the chance to perform on stage at the Dundee Rep.

Normally when you join the Community Adult Group of the Dundee Rep you are involved in weekly workshops. I never thought in my wildest dreams that I would end up on stage after only being there for 2 months. Certainly worth the wait! The play "The Bridge" was on for two nights in July. A very well written and directed play with a cast of over 25 young and old, both non disabled and disabled.

"The Bridge" is loosely based on the tragic events of the Tay Rail Bridge Disaster in December 1879, a rather drunken woman and a present day wedding, going in and out of two time periods, making it an absorbing 1hr production for the audience.

Learning lines is certainly no easy task especially when you have 3 parts to play. There was a fair amount of moving around on stage which at times was very dark. Not easy when driving a turbo charged powered wheelchair. There was a break dancing section, now that was fun! A lot of gasps from the audience as I was whisked out my wheelchair, doing the splits and spinning on my elbow. Phew! I'm glad I got the spins right! Great Memories, role on the next Performance!

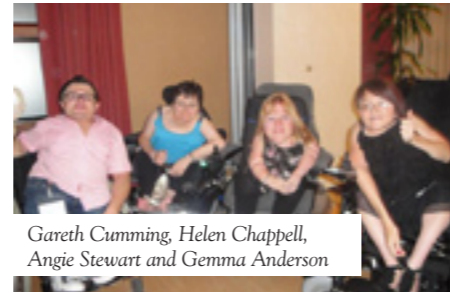
BBS CONFERENCE *In Pictures*



Young BBS members enjoying the event



The Mayor of Charnwood Councillor Jill Vincent and Jill Nelis



Gareth Cumming, Helen Chappell, Angie Stewart and Gemma Anderson



Kids club wearing t-shirts designed at conference



Dog for the Disabled dog Frodo 'working'



Winning quiz team



Elaine and Martin Rush



Dancing at the disco on Saturday night

BBS & OIF USA: UNBREAKABLE SPIRIT

I was thrilled at the chance to visit Portland Oregon USA and represent our charity. Our sister charity's conference was a huge success and attended by around 500 delegates. I conveyed best wishes from our Charity and presented a beautiful silver quaiche from our Trustees 'a sign of friendship'. I attended as many workshops and talks as I could manage, and met amongst others the famous Dr Francis Glorion, and took great inspiration from the way OIF communicate with members stateside. I tried to emulate some of those ideas at our recent Conference including our Clothes Swap Shop. Some treatments in America and medical opinion on bisphosphonates and treatment sometimes differ, but the same challenges facing members with OI seem universal. I struck up many friendships and was thrilled that they announced they were embarking on a Youth Presence on their board – something we have already achieved and am sure we can collaborate with them going forward. One idea would be to mount more joined up campaigning like celebrating Wishbone Day May 6th and exploring exchange visits for members.



Patricia with silver quaiche presentation to Tracy Hart-Smith CEO and President of the OIF USA - Sharon Trahan.

BBS Special Project HISTORY BONES

Safe at last. All the precious archive material collected since 1968 has been rescued and preserved and we are pleased to report that we have now secured funding to cover the cost of the exciting project. The historians and specialist team from the University of Dundee are busily working on cataloguing the information, leaflets, pictures and important documents all to be recorded for posterity. We will keep you posted on the progress of this important work. The next stage will involve the Archivists interviewing the charity founder Mrs Margaret Grant MBE and Sheena Moreland Hon Secretary to record stories and events from down the years. It will be exciting to see and hear the final product.



Trustees - Margaret Grant, Local Councillors' McPherson, McCreedy and Barrie from Dundee City Council and Trustee Mark Ross.



Patricia Osborne, Minister of Scottish Parliament Ms Shona Robison and Caroline Brown - Senior Archivist - University of Dundee.

SHEENA'S REPORT ON THE CONFERENCE

At the AGM 2010 there were 67 voting members present, including 11 proxy votes – the meeting was quorate. Robert W Gordon from Carlisle, Cumbria, as sole applicant for the post of Treasurer was elected for a period of 3 years. Robert is married with a daughter who has OI and is a qualified Chartered Accountant with sound voluntary experience and also runs a successful consultancy firm with his wife.

There were 6 ordinary Trustee nominations for 4 places: Malcolm Gourlay, John R Phillips, Michael C Phillipson, Mark Ross, James Sageman and Harry Venet. Successful applicants were: John R Phillips, Mark Ross, James Sageman and Harry Venet all being elected for 3 years.

John R Phillips is a partner in Jones Day, the global law firm and specialises in mergers and acquisitions, with a particular focus on cross-border transactions. He has over twenty years of legal experience and is regularly mentioned in both Chambers and Legal 500, the two main UK legal directories. John was introduced to the charity in June 1999 by an employee of Jones Day, whose daughter has OI. Since then, he has raised funds for the charity through events from a sports auction to sponsored runs, including the New York Marathon.

On behalf of the Trustees I would like to express a sincere welcome to Robert and John and also to Mark, James and Harry for continuing to support the work of the Board

The Trustees also thank both Malcolm Gourlay and Michael C Phillipson who were unsuccessful on this occasion in being elected as Trustees. We convey our gratitude to them both for their interest in applying, and know that both will continue to give their full support to our various projects and plans.

I am almost too old to be rushing about as I used to, and therefore curtailed much of my involvement at this year's conference, although I managed to keep a close eye on all that was going on. I was delighted to catch up with many members old and new, and my job this year was chiefly manning the new Rachel Galley jewellery stand and supervising the grand raffle prize draw which was a great success as ever. I was very pleased that we raised over £500 in sales on jewellery and the combined fundraising gathered



in at our new family dinner event raised a total of £2432.11 and came from both the raffle, the dinner envelopes, and an impromptu tombola organised by Angela and Andrew Mills.

The Conference weekend worked out extremely well and I received many positive reports from members and their families. One member said "There was a lot that went on at conference and we enjoyed every moment of it" another said "I feel that the society now feels to be a dynamic and professional organisation, but has not lost its routes and family feel, which is quite an achievement and mainly credited to a very well skilled and dedicated board of Trustees, excellent leadership, management and enthusiastic staff team. Well done everyone!" I would urge anyone who has not already submitted a feedback form to do so by visiting our website or contacting the office for a copy of the form.

I thoroughly enjoyed meeting everyone, but it was also tinged with some sadness to remember that my dear friend Jill Bettany from Stoke on Trent sadly passed away on 26th June this year.

Grand prize draw

Drawn on Saturday 25th September 2010

1st Prize	£500	Julie Lemon, Lisburn, N. Ireland
2nd Prize	£100	Fiona Barton, Dundee
3rd Prize	£100	Pat Power, Manchester
4th Prize	£100	Jill Nelis, Belfast, N. Ireland
5th Prize	£100	Steve Davidson, Dundee
6th Prize	£100	Paul Atkins, Stockton-on-Tees

Sheena Moreland

BBS OUT AND ABOUT

By Jill Murdoch

I can't believe it – I have been with the BBS for six months already, how time flies! I have thoroughly enjoyed the opportunities I have had to attend events and meet lots of wonderful people at VOICE 2010, Sheffield Children's Hospital Fun Day and of course the Annual Conference. I have many plans for the coming months to get out and about and meet more of our members. A priority is to get over to Northern Ireland for a Christmas Lunch on Saturday 11th December. There has been a suggestion by a member to hold an informal get together in the Ipswich area in the coming months, if this is something you would be interested in please get in touch. Please do let me know your suggestions about where we should be thinking about holding future regional meetings.

On 13th November Patricia, Christine and I are supporting the Royal Hospital for Sick Children, Yorkhill in Glasgow to hold a Parents/Carers Information day, the event looks set to be a great day with information on OT support, Healthy Bones, benefits, Motability and more. This is collaboration between the BBS, National Osteoporosis Society and Short Stature Scotland which is a first! Photos and a report will follow on our website.

VOICE 2011

Plans are well underway for VOICE 2011. Thank you to all those who filled in the online questionnaire designed by Trustee Catherine Potterton, it has given us an excellent base for our planning of the next youth event. Please keep an eye on the VOICE page of the BBS website for updates on the event planned for 15th to 17th April 2011.

IMPORTANT NEWS: NEW BANK ACCOUNT

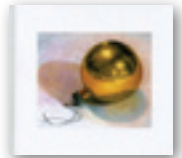
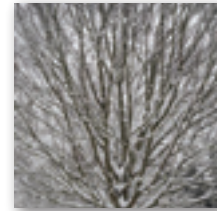
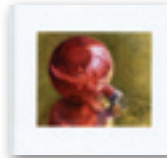
From the 11th of November 2010, The Brittle Bone Society's account will be changed. Please make note of our new bank details which are as follow and please make all future donations into the new account.

Account name: The Brittle Bone Society
Sortcode: 83-5000
Account No: 10479306
Address of our bank: The Royal Bank of Scotland,
 Dundee Chief Office, 3 High St,
 Dundee, DD1 9LY

We have enclosed a membership form, if you are already a member please pass this on to a friend, colleague or family member who may be interested in becoming a member. You can also use the form to update us with any change of details or to give a donation.

BBS CARDS ARE NOW ON SALE READY FOR CHRISTMAS!

If you would like to order quality Christmas cards to benefit the Brittle Bone Society, they are now available. The cards (150mm square) have been photographed and produced by Wendy Hyams, one of our members, and are supplied either blank for your own message, or with the following wording inside: 'Seasons Greetings'.



1 card for £1.50 | 10 cards for £10 | 50 cards for £40

To order, please contact Wendy Hyams

Tel: 01727 837881 or email: info@wendyhyams.co.uk

SHELLY GETS MARRIED

BBS Finance Officer Shelly Liang got married in China on 24th September 2010. Everyone at the BBS wishes Shelly and her new husband Raymond great happiness in their future together.



Shelly with her new husband Raymond, Shelly's parents (seated) and friends who travelled from Scotland to attend her wedding celebration in China.



JEWELLERY

By Rachel Galley

Thanks to negotiations brokered by Trustee Emma Lewis we have managed to secure some beautifully designed 'wishbone' inspired jewellery by designer Rachel Galley, which was a big hit at our Conference. Please see below for price list of the items on offer if you want to help BBS funds and procure a lovely gift idea for Christmas. To order please call the office on 01382 204446, you can then either pay by credit/debit card or by sending in a cheque. Stocks of some items are limited so please contact the office quickly to avoid disappointment.

8mm Wishbone Earrings	£20.00
Wishbone Cuff links	£26.00
17cm Wishbone Bracelet	£38.00
Wishbone Pendant necklace	£25.00
Wishbone Clothes Pin	£22.00

As well as the jewellery we have our BBS t-shirts which now come in a choice of two colours – white with a blue logo (£5.00) and black with a white logo (£5.50).

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