

Fundraising news

Spring 2015



Barth Syndrome
Trust

Saving lives through education, advances in treatment, and finding a cure for Barth syndrome

We're making a difference

"We all have to work together...but it is an amazing milestone that we are now discussing possible treatments for Barth syndrome. It is an extremely exciting time."
Kate McCurdy, BSF Journal Spring 2015

Once again BST has some outstanding news to report. Donations, standing orders and fundraising activities have raised an amazing sum for such a small charity—£32,404 in 2014. This has enabled us to fund more research as well as supporting our families, eg with access to the Clinic and the latest knowledge of Barth syndrome. We are currently funding a research project in Scotland and co-funding two more with the Barth Syndrome Foundation, to which we are affiliated.

Progress is being made in research and treatments are becoming a realistic possibility in the years ahead, although such developments take time and there is a continuing need for fundraising. The Barth syndrome community is truly international, a family that extends across borders helping and supporting each other. It is as a community that we can make progress towards the day when Barth syndrome is beaten. Thank you all.

Nigel Moore, Treasurer

Fundraising in brief—thank you

- ♥ Generous donations were received from families in US, Europe and UK. Thank you very much.
- ♥ Our friends and families will use any celebration as an opportunity for donations. Gill Amos, Charlotte Sharpe and other anonymous revellers received donations for BST instead of birthday presents from their friends and family.
- ♥ The wedding of Kate Riseborough and Wendy Evans was another happy occasion for donations.
- ♥ Ice bucket challenges: Many rose to this challenge and responded on behalf of beloved boys, summarised by one of our families: *'In memory of all the boys we have lost, and to help all of those we continue to cherish.'*
- ♥ More buckets! Suzy regularly collects change



Photo by Alex 2015

Some of 'our boys' from UK and Europe (aged 5-25) relaxing after the clinic at the BST Family Day May 2015

- through 'bucket shakes' at Fordham's car boot sales. Thank you to the organisers, the donors and Suzy.
- ♥ Jane Mannering's slimming efforts for her son's wedding and her 'nephew William and all the boys who have Barth syndrome' have yielded results for BST and Jane.
- ♥ On 10 August 2014, Jocey Buly and friends cycled in the wind and rain on to finish the Prudential Ride London-Surrey 100. The organisers cut out the Surrey climbs of Box Hill and Leith Hill and their potentially dangerous descents under conditions of torrential rain and surface water. Undeterred, Jocey rode for BST and BSF and her parents matched donations received.
- ♥ BP Bruce Platform held another Festive Raffle and we were lucky to be chosen again. Thank you to the staff, Dave Farrell Charity Committee and Larry Salmon for nominating us again.
- ♥ Thank you to our friends in Wales for:
 - *Another £60 from a book sale at HMRC Cardiff
 - *And from the Parish of Caerphilly, £100
- ♥ And from Scotland, £200 from the Sportman's Dinner at Kilwinning Phoenix Football Club.
- ♥ Static collecting boxes: Total since 2007 is £12,300, of which £1,650 came from the Horse Shoe, Downend!

In memory of Alasdair Gray

Alasdair Gray memorial fund



Alasdair Gray

Our son and brother to Cameron, Lewis and Fraser. Alasdair was born 12 days late on the 20th of October 2013 weighing 8lb 4oz.



In the early days Alasdair suffered from acid reflux. He had a couple of chest infections in his first 6 months and was struggling to gain weight. Alasdair was otherwise reaching the expected mile stones .



Initially the poor weight gain was put down to not being well when he had the chest infections. The time came for weaning and Alasdair didn't take to weaning like our other boys had, it was a struggle to get him to take most solids.

We began to think he had food allergies and were referred to the hospital for investigation. After a couple of nights in hospital we got home pending further tests and results. After just one night at home Alasdair just wasn't himself and we decided to return to the hospital with him. Things were quickly taken out of our hands as we watched our beautiful baby boy go from sitting up looking at us to passing out and being rushed to theatre with

an enlarged heart. Our whole world began to fall apart. Never had we imagined Alasdair was so poorly. Alasdair had a cardiac arrest and was resuscitated. After hours in theatre he was stabilised enough to transfer him to The Royal Hospital for Sick Children in Glasgow, where he had another cardiac arrest. Despite intensive care his heart wasn't strong enough and we had to say goodbye to him. He was just 9 months old.



We were initially told that it was possible that a virus had attacked Alasdair's heart. It wasn't until a few months later results came back saying Alasdair had Barth syndrome. Something we had never heard of before.

When all you have are memories it becomes very important to keep the memories alive. We want to raise money for charities, raise awareness of Barth Syndrome and most importantly do something positive in Alasdair's name and keep his memory alive. *We want people to know Alasdair was here and remember him.*

Fundraising

Alasdair's Dad – Fraser wanted to start the fundraising and decided he would shave his beard. Alasdair used to love rubbing his hands over his Dads stubble and Fraser hadn't been able to shave since he was taken from us in July.

A raffle was also organised at Fraser's work.



In memory of Alasdair Gray

Continued from page 2

"We want people to know Alasdair was here and remember him."



Next we held a Messy Play day for pre-school children in our local town . . .



with a raffle . . .



and a baking stall.

The support shown has been amazing. With the help of all who have donated we have so far made a fantastic profit of £7181.44 including Gift Aid.

Our fundraising is not finished here though. In school, Lewis' (Alasdair's big brother) class were set the challenge of doing a talk on a charity they would like to raise money for and say why the charity was important to them. Lewis chose the Barth Syndrome Trust. The class had to pick a winner and will try and raise money for that charity. Lewis was extremely pleased when he came home saying they picked two charities to raise money for and one was his – BST. A car boot sale and a coffee morning have been mentioned so far!

We have more plans for fundraising and hopefully by the time the next newsletter comes out we will have more to report on what we are hoping will be an exciting and successful fundraiser, watch this space!

Thanks for taking the time to read about the fundraising efforts made in Alasdair's name so far.

Gone but never forgotten, always in our hearts and on our minds.

Alasdair Leonard Gray

Best wishes from the Gray family,
Laura, Fraser & boys x

In memory of Philip Brown

Eclipse Proclaim Personal Injury Awards



Philip Brown
22.05.2005—29.09.2009

Eclipse Legal Systems generously chose the Barth Syndrome Trust as the charity of the evening at the Proclaim Personal Injury Awards held on 12th November 2014 at Grange St Paul's, London.

The exciting news just received is that Eclipse has again raised money for BST, £574.55, at the Claims Innovation Awards on 4th June 2015 in Manchester.

Thank you all and thank you to Helen Gibson and Eclipse for organising both fundraisers for us. We are grateful for your continued generous support.



Eclipse's Tracy Blencowe and Josh Widdicombe at the Personal Injury Awards with the cheque for £2658.51.

The fundraising was in memory of Philip Brown, whose father is a member of staff. The Awards, which celebrate outstanding contributions from individuals and claims service providers, were hosted by comedian, Josh Widdicombe, and were attended by over 400 guests. They contributed a total of £2658.51 for BST.

Karen Olden's London to Cambridge Bike Ride

I spent the summer of 2014 training for the London to Cambridge Bike Ride which took place in July. I rustled up some friends to take part and we spent many a Sunday riding around South



Cambridgeshire into Essex to practise for the big event. I have only just taken up cycling and did invest in a new racer to make the ride more comfortable and also some padded cycling shorts to cushion the ride!

It was an early 5am start to put the bikes into lorries and take the coach to London. The day was warm but luckily there were plenty of water and refreshment stops for us, and once we had battled the

hills on the course coming back into Cambridge after four and a half hours in the saddle to my home town was a welcome sight. The event was very well managed and the crowds were out in force to cheer us on.

The one thing that keeps me going is the image in my mind of Mitchell, a boy who is close to my heart and whom I feel lucky to know, and all of the other brave little boys and their families who are affected by Barth syndrome. As for next year, I will be looking for a new challenge and I will keep you posted!

See Suzy's fundraising, page 5



Mitchell



Karen with her medal

Terri Allison's fundraising diary

Quiz in Basingstoke

On 28th November 2014, George White, our very classy quiz master, again put together some challenging questions to 62 friends who came along to support the Trust at the annual quiz. The event was held again at the indoor bowling club and all participants enjoyed a meal of either, scampi, chicken, sausages or lasagne all with piping hot chips. As always the teams were constantly watching the scores to see who was coming out on top and friendly banter enhanced the evening's fun. BST was given a cheque for £290.50.

Body Shop demonstration –10th March

For the first time we tried a fundraiser in conjunction with an established High Street Store. I met Janet Kirkham, a representative of The Body Shop, in Devizes where she was selling products at a fayre. After a short chat she agreed to come to Oakley to help raise some money for BST.

After much planning, we hired a hall and although the evening was very well publicised, sadly only 19 people attended. However, it was a lot of fun and Amy a very pretty young girl volunteered to be a 'model' for the facial products.

Our grateful thanks go to Annick Manton who gave a very moving account of Barth syndrome and how it affects the boys, Veronica Pettigrew and Janet Cook for serving tea and coffee and special thanks to Celia Howlett who helped enormously behind the scenes and with the poster and advertising. The Trust was given £198.68 from the evening.

Annual BST Tennis Tournament

With the prospect of rain again the annual tennis tournament took place on Sunday 26th April 2015. Only 24 players were available, but I was overwhelmed by donations from friends. Anne Ward and Mary Williams again made numerous cakes and sandwiches which I think is the best attraction on the day. We also ran our usual raffle with donated prizes. This year we had two winners in the ladies' section, Diane Yarrall and Jacky Baxter and for probably the fourth time, Eric McCann won the men's section. Our grateful thanks to Oakley Tennis Club and all friends who donated cakes and raffle prizes.

The Trust received £407 from the event.

Tennis League Quiz

The Tennis League quiz was again won by our friends on Colin Philimore's team. This year they split the winnings between St Michael's Hospice, Basingstoke and BST. We received £198.

Hoping to run another quiz later in the year.

Very best wishes

Terri

Bat and Ball Club

Our staunch supporters at the Bat and Ball Club sent a very generous £320 donation raised from 'fines' when the players met in the Channel Islands for their 2014 table tennis tournament. The club has been supporting us for many years. Thank you all very much for batting for our boys again.



Fundraising by Mitchell's mother, Suzy, and friends

- ♥Pennies collection at Yvonne's work
- ♥Veronica Turner's Christmas raffle
- ♥Football card raffle
- ♥Other raffles
- ♥Collecting boxes in shops
- ♥Facebook sales
- ♥Bingo and donations instead of Christmas cards
- ♥Evening at work fines
- ♥School collection
- ♥Give as You Earn

Sharon and Steve and family

'The Trust is part of our lives and we have to support them as much as they help support William and us.'
Steve

Hever Castle Run or Dye

Sharon did the 5km Hever Castle Run or Dye on 4th October and donations exceeded her target. From her webpage: 'Had great fun completing my first charity run and a huge thank you to Vicky who ran with me. Lots of laughs along the way and getting soaked in the rain, dancing and throwing dye at each other just added to the day! Thank you to everyone who donated, it means such a lot.'



Sharon and Vicky at the Run or Dye



Runners were blasted with coloured showers of dye for each kilometre completed. They started the race in white and finished "looking like a rainbow".

From Hever Castle website.

Goodbye toenails

After dipping my toe into the Marathon world in September 2013, I discovered a perverse yearning to do more – but how to disguise this bizarre behaviour? I know, I'll tell everyone I'm fundraising for the Barth Syndrome Trust and I think I got away with it. Final tally for 2014 was 13 Marathons (plus one other for a prior commitment) for the Trust.

Thanks have to be said to some very generous sponsors, many of whom have chucked money in more than once and especially to my support team (Sharon, Emily and William) who have to put up with constant run chat, calendar fights, mountains of trainers and some of the smelliest running gear you could imagine.

The support team have been known to appear at some of the races but I notice they favour the warmer

Spotty the Bear finds a new home

My second fundraising challenge . . . and who wouldn't want to win a huge cuddly bear! I had 100 names to be chosen and with the help of family and friends and William's nursery we not only raised £220 but my great-aunt donated her savings from her heating bill and I am proud to say £280 was the end total. The name drawn was Spotty and a little girl at the nursery became the proud new owner of the polar bear and lots of chocolate! Thank you to everyone once again. Now, what to do next?

Sharon



William and Emily proudly display Dad's medals.

parts of the year and those races that benefit from cafes and beach fronts. William has attempted a couple of jog-alongs but he seems confused as to why daddy keeps running away from him? Emily is close to being banned from running in with me at the end, she is just a bit too quick and a 100 metre sprint is not what I need at that point.

Obviously 2015 requires at least 15 marathons (I think 16 are booked up for so far) but we needed something to round the fundraising off and I find myself signed up for 5 in 5 at the end of November. The ongoing challenge is to join the 100 Marathon Club and run 100 26.2 mile races for BST.

Goodbye toenails.

Steve

<https://www.justgiving.com/RunMore-Cotch-RunMore>

Fundraising news from loyal friends

Nicholas's Kitchen

Pam Holmes, is back in Nicholas's Kitchen, her fundraising company set up to help BST. She has raised AUS\$800. This was matched by **Treasury Wine Estates**, her employer. We thank them very much for their generosity in supporting Pam's fundraising again.

Shown here is one of her Indian cookery classes. Pam has also organised a stall at a weekly Organic market to sell her spices and pickles and promote her curries, all profits going to BST.



Pam has raised thousands of pounds for BST through Nicholas's Kitchen, with Treasury Wine Estates generously matching some of the amounts she raised. Her great-nephew, Nick, is the inspiration for all her hard work.



Wilf Smith... Something completely different

by Julie

We first met the wonderful Wilf Smith at Bakewell cattle market when Dillon started going with his Grandad. Since then he has become a really good



Dillon

friend and has done several very gruelling challenges for Barth Syndrome Trust and his latest escapade was no exception. He nearly gave his lovely wife, Brenda, a heart attack just thinking about it. Wilf is 68.

He went to an airfield at Hibaldstow on a sunny day in May and jumped from an aeroplane at 15,000 feet. The adrenaline must have been pumping in the lead up to his training and the jump looked terrific. He looked really good in his jump suit and his smile was much bigger when he was back on firm ground. He must have enjoyed it because he wants to do it again in the summer.

He took part in a vintage tractor run a few days after his jump. Wilf rode a 1964 International B414 tractor from Spilsby to Louth. The organisers, Andrew and Sarah Dunnington from Scrembly,

Spilsby, give any money raised to a charity. This year, because of Wilf's enthusiasm, they donated the money, £220, to his jump for the Barth Syndrome Trust. He would like to thank Andrew and Sarah for their kindness.

The total raised for the jump and the tractor run is £2,051.21.

Not only has he done all this himself, raising several thousands of pounds but he also has been talking to lots of people about Barth syndrome and why he is doing the things he does. I personally would like to thank him and Brenda for all the things that they do. They are amazing.



And 'high five' to Wilf (left), Brenda, Wilf's donors and Julie from all the BST families .

Time, advice and donations 2014 - 2015

Thank you to friends of the Barth Syndrome Trust

There is no such thing as a small donation, either of time or of money. We are grateful for your support. To save space and to make the most of your donation, we only note amounts over £25 in this section. Because of the large number of sponsors again this half-year we have been unable to list each one but thank you for supporting your friends who ran, walked, cycled, sky-dived, drove a tractor, slimmed, shaved and accepted other challenges for BST. If your name has been omitted from this list by mistake, we apologise. Please let us know so we can amend it.

Donations and funds from events were received in loving memory of

Margaret Amos	24.09.1928—28.06.2014	Alasdair Leonard Gray	20.10.2013—23.07.2014
Philip Brown (5th Anniversary)	22.05.2005—29.09.2009	Jack Reddin	22.12.2009—29.12.2009
		Sebastian Vavasour	24.06.2011—11.12.2013

And all the boys who remain in our hearts

Alasdair Gray Memorial Fund
Allen, Helen
Allison, Terri
Amanda Jones
Amos, Gill
Amos, Joan & George
Anderson, Tommy & Allanna
Barker Brooks Communications Ltd
Barratt, Linda & John
Barth France
Barth Syndrome Foundation
Barth Syndrome Foundation Ca
Bartholomew, Mr P
Basingstoke Table Tennis Club
Bat & Ball Club
Bateman, Cath
Bath, James, Kathryn & Sponsors
Bath, Mrs A
Batten, Emma
Beaton, Sophie
Billin, Abigail
Bostock, Gerrard
Bowron, Ann
BP Bruce Platform raffle
Briggs, Steve
Brown, Alan & Lange, Maike
Brown, Michael
Bull, David & Sarah
Bull, Lyn
Buly, Alex
Buly, Jocey & Sponsors
Burchell, Jan
Buston, Sarah
Caerphilly, Parish of
Calcutt, John & Tina
Caldwell, Kerry
Champneys Forest Mere
Chance, Susan
Chives, D. & J.
Clark, Michael
Clayton, Nicol
Cleaver, Dene
Coleman, Michael & Helen
Connie Sinclair
Cook, Janet
Cooper, Sam
Cotterill, Steve, Sharon & Sponsors

Craigie, Ray & Patricia
Crawford, Eleanor & Michael
Damin, Claudio, Mandy, Connor, Lia
Damin, Marco, Michaela
Damin, Nori
Dave Farrell Charity Com, BP Bruce
Davies Turner
Degive, Bernard
Docendo Discimus Lodge
Dummer Gold Club
Dummer Golf Club Seniors
Dunnington, Andrew & Sarah
Easterbrook, Ralph & Isabel
Eclipse Legal Team
Evans, Trevor
Exon, Anne
Farmilo, Catherine & Sponsors
Farrow, Anne & Roy
Fernleigh Court Girls
Finkley Down Farm, Andover
Fletcher, James
Flood, Kim
Fordham C of E Primary School
Forsey, Dr Jon
Fox-Williamson, Patricia
France, Gemma
Frost, Michael & Angie
Garratt, Fr Jeremy
Garrett, Vanessa
Gibson, Helen
Goodman, Dani
Green, Suzy, Jerry & Mitchell
Griffiths, Kimberley
Gunatilleke, Leah
Hadfield, Susan
Hardy, Gemma & Sponsors
Henderson, Paula & Clarke Family
HgCapital
HM Revenue and Customs, Cardiff
Hogg, Craig
Holmes, Pam
Horse Shoe, Downend
Howlett, Celia
HSBC Bristol
Jeffrey, Alison & Mark
Johnson's Dry Cleaning
Jones, Amanda

Jones, Cynthia
Jones, Lucy
Jones, Patricia & Sponsors
Jones, Patrick
Kilwinning Phoenix Football Club
Kirkham, Janet
Kvernland, Alexandra
Lallemand Egueur, Madeleine
Lawrence, Sheila
Lomer, David
Mackay, Lorna
MacPhee, Lynne & Family
Mannerling, Joan
Manton, Joan
Manton, Rob & Annick
Manydown Farm Shop
Marks, Helen
Martin, Dr Rob
Maynard, Mr and Jr J
Maynard, Muriel
McCarter, Rosemary
McGown, Angela
McSkimming, Michael
Moore, Nigel & Lorna
Morrison, Elizabeth & Sponsors
Morrison, F.
Murray, Joan
Neville, M
Newbury-Ecob, Prof Ruth
NHS Barth Syndrome Service
Nicol, Charlotte
Noah's Ark Zoo Farm, Bristol
Nyack, Adrian
Oakley Lawn Tennis Club
Olden, Karen & Sponsors
Parmley, Alex
Payne, Gary
Perks, Anna
Pettigrew, Veronica
Philimore, Colin
Phoenix International Charity
Platform
Rafferty, Faye
Reddin, Mick & Judi
Riddiford, Debbie
Riseborough/Evans, Kate & Wendy
Rodgers, Ian & Brigid

Salmon, Lawrence
Salmon, Robertina
Schlapak, Sonja
Sedefian, Lynda
Sharpe, Charlotte, Nick & donors
Shaw, Eddie & Sue
Shaw, M
Short, Stephanie
Simpson, Sue
Skerratt, Mrs E
Smith, Wilf
Stevens, Louise
Steward, Dr Colin & Christine
Strathdee, Dr D
Sutherland, Fiona
Sutherland, Laura & Gray, Fraser
Swennen, Family
Taylor, Family
Taylor, Guy & Sponsors
Taylor, Jenny
Taylor, Mr & Mrs
Test Way Walkers & Sponsors
Thomson, Dolores & Russell
Treasury Wine Estates, Australia
Trivett, Barbara
Turner, Veronica
van Loo, Jo & Albert
Vavasour, Eric & Isabelle
Vavasour, Joe & Laura
Venkatchellum, Mezie
Vogt, Patricia
Waddell, Laura
Wallace, Philip
Walsh, Winifred
Ward, Barry & Anne
Ward, Juliet
Warner, Rosemary
Whitaker, Louise
White, George
Williams A. N
Williams, Mary
Wilson, Sarah
Woodward, Ian & Tracy
Woolley, Julie & Scott
Wyggeston & Queen Elizabeth I, Staff
Yeoman, Roy

Tell us about it! We would love to hear your fundraising news. Your event could inspire others to help our boys. Feel free to contact us for leaflets and balloons when planning an event. Email fundraising@barthsyndrome.org.uk

Barth Syndrome Trust, I The Vikings, Romsey, SO51 5RG : www.barthsyndrome.org.uk