

## Thank you for your generosity

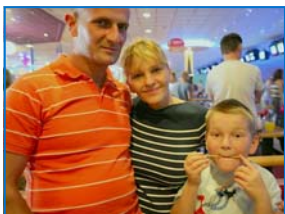
This newsletter celebrates the generosity of our families and friends not only in the UK and Europe, but around the world. We report on fundraising that has taken place since our last newsletter.

### Fundraising round-up

These are difficult times for many of our donors, but again we have been moved by the kindness and thoughtfulness of colleagues, schools, clubs and individual donors. As always, our boys and their struggles have inspired this fundraising and these donations. [A heartfelt thank you to each and every one of our supporters.](#)

♥ **Bat and Ball Club:** As we closed last year we gave provisional figures for the Bat and Ball Club who gather in Jersey and Guernsey from all over the UK to play Table Tennis. The total donated through their 'fines' in 2013 was £360! We have had so much support and interest from this group of players over the years.

♥ **Courthouse Junior School** in Maidenhead sent £400 collected at their Christmas Concerts. A very welcome surprise. Thank you to the parents and children.



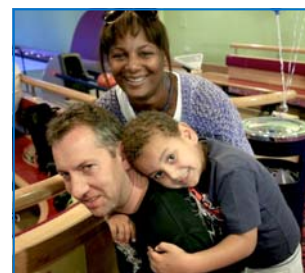
♥ **Jacqui Lester** walked the beautiful Test Way with the Romsey Rotary Club to raise £107.

♥ **Bridget and Alan Phillips** recently celebrated their 50th birthdays (Congratulations!) at a joint hoe-down party with donations instead of presents. They shared the funds between BST and the Oncology unit at Derby hospital where Alan's father died last year. We received over £600. What a party!

♥ Our faithful friends at **Derbyshire Dales Council** have been busy again. Environmental Health staff, Pat and Eileen sold a cake for BST. Thank you to Julie Woolley for raising awareness and funds in her area.

♥ **Brenda Smith** has been collecting her pennies. As the saying goes, "Look after your pennies and..."

♥ Trustee, **Suzy Green's** coffee mornings, a nearly new sale, eBay sales, 'bucket shakes' and other events raised over £2000! →



♥ **Eleanor Crawford** ran the Great Scottish Run again and raised over £500. Well done!

♥ **BP Bruce Platform staff: Dave Farrell Charity Committee** raised £200 through their festive raffle. Thank you to BP Bruce Platform and Larry Salmon for proposing BST.

♥ Gill Amos, her mother, Margaret Amos and sister, Jan Burchell raised £173 at a car boot sale.

♥ Standing orders and Give as you Earn schemes bring BST a steady income, and being predictable, help with planning.

♥ Single donations have also increased this year. We value each donation and the messages of encouragement too. One very kind supporter who tithes her income for charity donations gave us a contribution.

♥ **Cara Roberts-Collins and Debbie Riddiford**, of the Barth Syndrome Service at the Bristol Royal Hospital for Children, ran the Bristol 10K and Cara also completed the New Forest Triathlon. It's not too late to sponsor their efforts for BST by cheque to BST or [www.bmycharity.com/](http://www.bmycharity.com/)

The shaver's progress



T-shirt -Many nations—one mission



First cut



Full front

## Tommy's Christmas Hairshave on the Buzzard Platform

*from our Bmycharity pages: at Christmas 2012:*

"Many of you know already that my youngest son has Barth syndrome and I am just trying to raise some much needed funds for this wonderful charity that is so close to my heart. Please support if you can, any small amount makes a difference and is truly appreciated. I always like to have a full thick beard and my hair long during the winter months to help keep me warm lol, but after some persuasion from my workmates I am willing to shave it all off to help raise some funds and awareness for the Barth Syndrome Trust.

I am away from my family this Christmas at work but have brought my shaver out and the boys are gonna shave it off on Christmas Day, although I think they want me to walk around with one side shaved for one day then it comes all off the next day!

I wish you and your families a very Merry Christmas."



It takes a brave man to let his workmates loose on his hair with a shaver. Our spy on the Buzzard Platform recorded the process and the resultant fetching hairstyle, as you can see, was worth every penny raised.

Well done to Tommy, all on the Buzzard Platform, including the barbers, and family and friends, and the worldwide Barth family.

Tommy's 130 sponsors donated a total of £2030. Thank you all.

Thinking of supporting our work?

*giftaid it*



**Terri Allison reports** on fundraising in Basingstoke, Overton and Oakley: annual events which have become part of the Basingstoke area calendar. Terri was one of our first volunteers, inspired by Nick, now 15. She has raised thousands of pounds 'for the boys' since 2005.

## The Overton Quiz



From our archives:  
Richard Oram in action

Over 50 people attended the annual BST quiz in Overton Methodist Hall on Saturday 23rd March and brought in a profit of £428.76.

The questions were again compiled and presented by Richard and Heather Oram of Overton. Sadly it was the last quiz they are able to run for us

and to show our gratitude they were presented with a commemorative cut glass bowl by Annick Manton, grandmother of Nicholas Damin.

The evening was again a great success with plenty to eat and lots of very testing questions with the inevitable challenges on dubious answers.

We wish Richard and Heather every success in their new venture, charity work abroad, and thank them both again for their time and dedication to fundraising for the Trust.

## 9th BST Tennis Tournament

28th April 2013 at Oakley Tennis Club

Possibly the biggest stress in organising any outdoor event is the uncertainty of the weather and although one of the coldest days the annual BST tennis tournament has seen, the rain stayed away and 36 players enjoyed an afternoon of good tennis and lots of tea, coffee and scrumptious cakes.



The Winners

This year's event was won by 13 year-old Liam Hignett from Overton, who looks set to have a very promising future in the game. He beat some accomplished tennis players and was a

popular winner. Oakley's Julie Frankland was the winner of the battle of the ladies.

BST remain indebted to Oakley Tennis Club for their continued support in allowing us to run the event at the club and for generously supplying the balls.

Grateful thanks must also go to Anne Ward and Mary Williams who not only made cakes and sandwiches but served and washed up throughout the entire afternoon. Thank you ladies, the day would not run as smoothly without you nor would we make as much money for the boys. Thanks also to Oakley player, Richard Baxter, who was the brains behind the order of play. And to Barry Ward who took the photos. As always the day is not only supported by the players who battle for the tennis honours but many of them, and friends in the area, bake cakes and donate raffle prizes to add to our overall total of £500. One wonderful cake was auctioned to raise £15.50.

*Thank you to Terri for all her hard work to make this annual tournament a success.*

## Table Tennis Quiz

80 friends and keen quiz enthusiasts gathered at Loddon Vale, Basingstoke on Friday 1st February to test their knowledge and enjoy an evening of good food and good company.

George White compiled and presented the quiz in his usual inimitable way. His strange, 'pot luck' round remains unique and thoroughly enjoyable.

Many thanks to all who supported the event and to George for all his hard work. A profit of £440 was shared between the Table Tennis League and Barth Syndrome Trust.



Liam Hignett and Terri Allison

## Rossett School Yr 9 Fundraise for the Barth Syndrome Trust

Year 9 of Rossett School in Harrogate were encouraged to develop a social enterprise activity for a worthy cause as part of the *Citizenship Foundations Giving Nation Challenge* <http://www.g-nation.org.uk/>.

Yr 9 chose BST as their charity after hearing about young Philip Brown, 22.5.2005-29.9.2009.

They tied in their fundraising with a Valentine's Day message service at the school. Students paid £1 for a gift with a message attached to be delivered. A production line processed heart-shaped chocolates and sweets to go with the messages. Thank you to everyone in Yr 9, Mrs Martin and the staff and students at Rossett School. You can be assured that all donations help us in our work. We are also grateful to you for raising awareness of Barth syndrome. Well done, Yr 9.



Heart-shaped sweets



Busy with sales



Writing the messages

### Doing some fundraising? Tell us about it!

We hope to continue to produce a fundraising newsletter twice a year if we have enough news. A quick email about your event could inspire others to help our boys. And don't forget to include photos!

We can provide leaflets, balloons and other material for your fundraising.

Email: [fundraising@barthsyndrome.org.uk](mailto:fundraising@barthsyndrome.org.uk) **before 5th October** in time for the autumn newsletter.

## My Charity Evening

by Karen Olden, Aunt of Mitchell

I held a Charity Evening at my home on 26<sup>th</sup> April 2013 to raise money for Barth and Macmillan. I was very well supported by local businesses and had more than 20 prizes in total. The raffle was drawn on the evening and we raised £407.50 and we also raised £150 on the evening for Macmillan by way of having cake sales and donations from people who had therapies and manicures when the raffle was drawn.

Local Cambridge businesses who support me include: Cambscuisine; Salon 5; Cambridge Lakes ; Cambridge Toy Shop; Shepreth Wildlife Park; Hannam's Wake Hub, Julie Burkin on behalf of Stella & Dot; Cam Yoga; Inders Kitchen.

*Thank you for all you do for the boys, Karen.*



## Donations were received in Loving Memory of

|                     |                                     |
|---------------------|-------------------------------------|
| Isaiah Chahal-Henry | 18 April 2011 – 8 January 2013      |
| Russell Riseborough | 4 June 1964—24 October 2012         |
| Oscar Stobart-Hook  | 26 October 2010 – 21 June 2011      |
| Benjy Thorpe        | 2 September 1994 — 17 November 2010 |
| Jack Reddin         | 22 December 2009 – 29 December 2009 |
| Philip Brown        | 22 May 2005 – 29 September 2009     |

## Collecting boxes

Several families have placed collecting boxes at their local shops and pubs. With the new Gift Aid Small Donations Scheme we can now receive an extra 25% Gift Aid from these boxes.

Collecting boxes are still providing us with a steady income, although volunteers have found it increasing difficult to place these boxes. Many chain stores are now required to support the charity chosen by head office. Other larger charities often have preference. But it is still worth trying to find places where our collection boxes would be welcome. Perhaps you know of a friendly shop or pub?

- Dave Bull has collected £8525 through static collecting boxes in Bristol since May 2007
- A box at D N Jenkins, Fordham has collected £300 in one year.
- Boxes at Manor Booze and Blue Merle in Derbyshire, Finkley Down Farm Park, Andover and Manydown Farm Shop, Basingstoke have all done well. Thank you to the managers and volunteers involved.



## Looking ahead . . .

### The Story

by Stephen Cotterill (Taken from his JustGiving page)

I'm running the Kent Coastal Marathon for the Barth Syndrome Trust! Please sponsor me at [RunMore-Cotch-RunMore](#)

William crashed with Heart Failure in January 2012, he proved us all wrong by fighting and his heart now functions almost normally. Whilst impressing his cardiologists with his improvements, other symptoms were noticed and William was diagnosed with Barth Syndrome in April 2013.

I'm trying to help the cause by running the Kent Coastal Marathon in September 2013. This will be my first marathon after deferring the 2013 London Marathon owing to an injury, which I'll now be running in 2014 for the Evelina Children's Heart Organisation (Another group whom have been part of William's life).

Thank you for taking the time to visit my JustGiving page.

## Other events planned

- Eddie Shaw, the Captain of the Senior Men's Team of Dummer Golf Club, has nominated the Barth Syndrome Trust as Charity of the Year. Thank you, Eddie for choosing BST. We wish you a successful year at Dummer Golf Club.
- Staff from Eclipse Legal are back running in memory of Philip Brown. Watch this space!
- Suzy Green plans even more fundraising, including an event at Morrisons in Lincoln.

## How you supported BST's work in 2012

In 2012 we received a total of £23,629 with fundraising events raising £13,074, and gifts and donations £10,500.

### Research

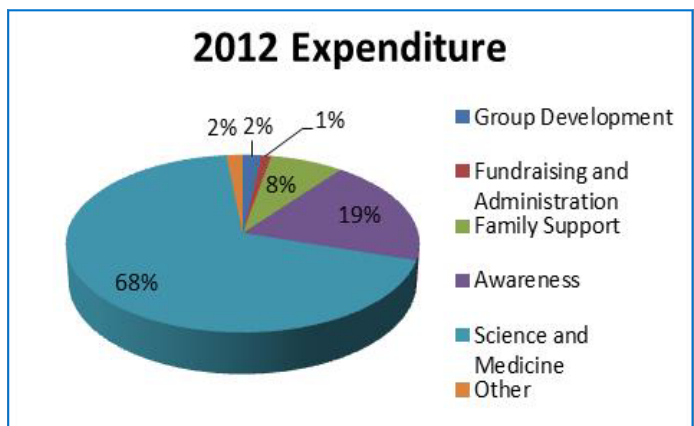
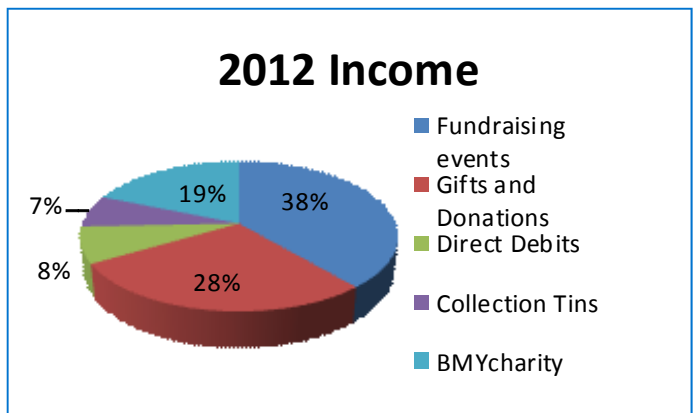
We have recently funded research by Prof. William T Pu of Boston Children's Hospital. We are grateful to our supporters for this opportunity to make progress towards our ultimate goal.

### Awareness

Our new website [www.barthsyndrome.org.uk](http://www.barthsyndrome.org.uk) is our most effective awareness tool and as soon as it was online we started receiving new enquiries. Thank you to Michaela and Marco Damin for all their hard work on this project and to families and volunteers for their feedback.

### Family Support

Our third largest expense. Family Days are important for the support of boys, their parents and siblings. It is also important that all families are able to attend the clinics every year. The clinic can be vital for the boys, it informs and supports the parents and helps all those with Barth syndrome by collecting information about this rare disorder.



### Donations and Sponsorship

BST has now registered with **JustGiving** and **Virgin Money Giving** for online fundraising. This is in a bid to make it easier for everyone to reach out to potential sponsors and donors and spread the word about your forthcoming events. We also still encourage you to continue using **Bmycharity.com** as an online fundraising portal.

## Gift Aid Small Donations Scheme

**25% extra on small anonymous cash donations!** <http://www.hmrc.gov.uk/charities/gasds/>

The Gift Aid Small Donations Scheme (GASDS) allows eligible charities to claim top-up payments from HM Revenue and Customs (HMRC) on small cash donations that they receive. The scheme applies to cash donations of £20 or less each, received after 6 April 2013.

BST could claim a top-up payment on up to £5,000 of small cash donations in a tax year subject to HMRC conditions being met. The donation must be in bank notes or coins. Donations made by cheque, credit card, text or bank transfer do not count.

This will apply to our Collecting Boxes and possibly some other events, but only if we follow HMRC rules and procedures to leave a clear audit trail. eg Exact moneys (all coins and notes) as collected must be recorded and banked physically into a BST account and not by internet. Please ask for more guidance.

# Grateful thanks to friends of the Barth Syndrome Trust

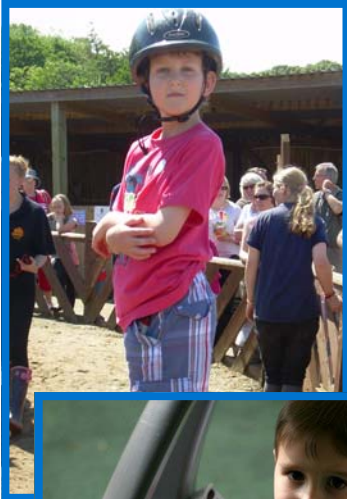
## Time, Advice and Donations, May 2012— May 2013

We are grateful for each and every donation of time and money, no matter how big or small. To save space and to make the most of your donation, we only note donations over £25 in this section. If your name has been omitted from this list by mistake, we apologise. Please let us know and we will amend it accordingly.

|   |  |  |  |
|---|--|--|--|
| Allen, Tiffini                                    | Damin, Marco, Michaela & Family        | Lallemand Family                                       | Roseberry Sports and Community College |
| Allison, Terri                                    | Damin, Nori                            | Lange, Maike & Brown, Alan                             | Rossett School, Yr 9                   |
| Amos, Gill & Eden                                 | Das Family                             | Latham, Daisy  | Royal Gwent Hospital, Staff            |
| Amos, Margaret                                    | Dawes, Rachel                          | Legal & General, Cardiff                               | Salmon, Gwen                           |
| Anderson, Thomas                                  | Derbyshire Dales District Council      | Lendrum, Caroline                                      | Salmon, Lawrence                       |
| Anderson, Tommy & Allanna: family & friends       | Revenues & Payroll Staff               | Lester, Jacqui   | Salmon, Robertina                      |
| Anderson, Tommy, Alanna & Family                  | Doherty-Bigara, Jérôme                 | Leveson, Patricia                                      | Salon at No 5                          |
| Andrews, Michelle                                 | Donald, Josh                           | Longhurst, Ally  | Schachat, Rally                        |
| At Bristol  | Drakakis, Helena                       | Loo, Jo & Albert van                                   | Schlapak, Gregor & Sonja               |
| Baillie, Dominic                                  | Drakakis, Mr & Mrs John                | Majumdar, Dr Arnie Mannes, Florence & Philippe         | Serra-Palmer, Mrs M                    |
| Bargain Booze, South Normanton                    | Durocher-Yvon, Dominique               | Manor Booze  | Setton, Amanda                         |
| Barratt, John & Linda                             | Easterbrook, Mr & Mrs A                | Manton, Annick & Rob                                   | Sharpe, Charlotte, Nick & Family       |
| Barth France                                      | Easterbrook, Ralph & Isabel and Family | Manton, Greg & Kerry-Ann                               | Shaw, Eddie                            |
| Barth Syndrome Foundation Canada                  | Edwards, Mr & Mrs G                    | Manton, Joan   | Shepreth Wildlife Park                 |
| Barth Syndrome Foundation, Inc.                   | Engelbrecht, Sally                     | Manydown Farm  | Simmons, Robert                        |
| Barth Trust of South Africa                       | Evans, Wendy                           | Marley, Valerie  | Smith, Brenda & Wilf                   |
| Bat & Ball Club                                   | Farrow, Rachel & Mark Skerratt         | Martin, Dr Robin                                       | South Wales Mountaineering Club        |
| Bath, Mrs AA                                      | Ferguson, Storm                        | Martin, Mrs L  | St Catherine's Church, Caerphilly      |
| Baxter, Imogen                                    | Finkley Down Farm Park                 | May, Derek   | St Dunstan's Church Community Café,    |
| Baxter, Richard                                   | Fraser, Matthew                        | McGregor, D  | Ashurst Wood                           |
| Baxter-Smith, Oliver                              | Fraser, Pauline                        | Merce , Mrs K  | Stagg, Lizzie & Kevin                  |
| Bonardi, Sally                                    | Frost, Michael & Angie                 | Michener, Kathryn                                      | Steele, Kenny & Drakakis, Alexia       |
| Bowen, Michael and Shelley                        | Garratt, Dr Vanessa                    | Moore, Nigel & Lorna                                   | Steward, Dr Colin and Christine        |
| Bowron, Dr Ann                                    | Gibson, Eleanor                        | Morby, Hannah  | Stinchcombe, Dennis, Louis & Michelle  |
| BP Bruce Platform, Dave Farrell Committee         | Gillian, Jack                          | Murphy, Helen  | Stobart-Hook, Barry & Nicolette        |
| Bray, Paul  | Gilmour, Mark, Lisa and Scott          | Murray Craig   | Stobart-Hook, Guy & Liz                |
| Brazier, Grace                                    | Goodman, Dani                          | Newbury-Ecob, Dr. Ruth                                 | Stone, Dr Janet                        |
| Brunold, CV                                       | Grant, Catherine & Alec                | Nicholas, Hannah                                       | Swennen Family                         |
| Bull, Lyn   | Grant, David                           | Nicol, Charlotte                                       | Symonds, Alistair                      |
| Bull, Sarah & Dave                                | Green, Jerry & Suzy                    | Norgate, Mrs Christine @Kings' School                  | Temple, Ailsa                          |
| Burchell, Jan                                     | Grundy, Edward                         | Nyack, Adrian  | Thomson, Nigel                         |
| Burchell, Jan & Roy                               | Hall, Annie                            | Oakley Tennis Club                                     | Thorpe, Astrid                         |
| Burkin, Julie                                     | Hamer, Araminta                        | Olden, Karen   | Thorpe, Jeremy                         |
| Buzzard Oil Platform: Tommy Anderson's Colleagues | Hanger, Lesley                         | Olden, Lee   | Thorpe, Nigel                          |
| Caerphilly Masons Arms                            | Hannam's Wake Hub                      | Oram, Richard and Heather                              | Thorpe, Thomas                         |
| Caldwell, Kerry                                   | Harris, Tristan                        | Overton Methodist Church                               | Thyne, Hunter                          |
| Callcut, John & Tina                              | Haslam, PG                             | Overton Tennis Quiz Team                               | Todd, Ian                              |
| Cambridge Lakes                                   | Haycock, Joshua                        | Pants, Candice   | Treasury Wine Estates, Australia       |
| Cambridge Toy Shop                                | Hayes, Dr                              | Pettigrew, Veronica                                    | Tsai-Goodman, Dr Beverley              |
| Cambscuisine                                      | Hill, Saskia                           | Phillips, Alan & Bridget                               | Upfold, Rachel                         |
| Camyoga   | Hinton, James                          | Piette Feck, Astrid & Arthur                           | Verdon, Shelene                        |
| Catto, Greig                                      | HMRC Staff, Cardiff                    | Play Centre Staff, Bristol Royal Hospital for Children | Wald, Amy                              |
| Chahal, Debbie & Henry, Simon                     | Holdsworth, Daphne                     | Polar Bear Windows of Bristol                          | Ward, Anne and Barry                   |
| Challenger, Paul & Margaret                       | Holmes, Pam & Rowland                  | Rawlinson-Millichap, Dominic & Peter                   | Ware, Jenny                            |
| Chamberlain, S                                    | Holmes, Samantha                       | Reddin, Adam & Gemma                                   | Warner, Rosemary                       |
| Chin, Annie                                       | Homewood, Alison                       | Reddin, Mick & Judi                                    | West Family                            |
| City & Guilds, Cardiff                            | Hope, Chris & Robert                   | Rees, Gaynor   | West, Claire                           |
| Clayton, Nicol                                    | Horwood, Jane, Catfish Web Design      | Riddiford, Debbie                                      | Westgate Primary School                |
| Clements, Claire                                  | Howard, Chris                          | Riseborough , Ms K A                                   | White, George                          |
| Condliffe, Cynthia & David                        | Howe, Malcolm                          | Riseborough , Mr & Mrs L                               | White, Mark                            |
| Cotterill, Stephen & Sharon                       | Howell, H                              | Riseborough, Mr LR                                     | Whithorn, Sarah                        |
| Courthouse Junior School                          | HSBC, Bristol                          | Riseborough, Mrs Thelma                                | Williams, Mary                         |
| Crawford, Eleanor and Michael                     | Inder's Kitchen                        | Roberts-Collins, Cara                                  | Williams, Norman                       |
| Crissmann, Janique & Seb                          | Jenkins, Don                           | Rogers, Rev Dr Sarah                                   | Winn, Melese                           |
| Crowne, Dr Elizabeth                              | Jones, Patricia                        | Rook, Joyce, Newton St Cyres Meat                      | Wites, Wojciech & Agnieszka            |
| D.N. Jenkins Ltd, Fordham                         | King, Mrs J, Misses P & S              | Bingo  | Woodward, Tracy & Ian                  |
|   | Kings' School, Winchester              |  | Woolley, Scott & Julie                 |
|   | KSC Phoenix, Jay's football team       |  | Wright, Jess                           |

## Thank you for helping

With information available through our work and that of the Barth Syndrome Service, parents help their sons to try to lead normal lives. Meanwhile we continue to fund research that will bring us nearer to our goal.\*



### Barth syndrome

— a rare, serious genetic disorder that affects males. The main symptoms are:

- Heart failure (Cardiomyopathy)
- Recurrent infections (Neutropaenia)
- Muscle weakness / General fatigue
- Feeding problems / Growth delay

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

Until we reach our ultimate vision...

*A world in which Barth syndrome no longer causes suffering or loss of life.\**

[fundraising@barthsyndrome.org.uk](mailto:fundraising@barthsyndrome.org.uk)

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**Romsey**  
**SO51 5RG**

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[www.barthsyndrome.org.uk](http://www.barthsyndrome.org.uk)



**Donations to:** Barth Syndrome Trust, 20 Regal Drive, East Grinstead, RH19 4SB  
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