

## Neuroblastoma Research Symposium 2013



The Neuroblastoma Society held its 3rd Research Symposium in November at the BT Convention Centre overlooking the Liverpool Docks. This day and a half meeting dove-tailed with the end of the National Cancer Research Institute annual meeting, and featured 26 speakers, 31 poster presentations and an evening for networking. Over 100 delegates attended, mostly UK academics and clinicians with particular interest in improving treatments for 'high-risk' neuroblastoma.

Three aspects made it a particularly enjoyable and successful meeting. Firstly, discussion time was set aside at the end of each session, and this led to some great discussions between delegates and speakers, and we are grateful to the session Chairs (John Lunec, Deb Tweddle, Diana Moss, Louis Chesler and Daniel Morgenstern) for their introductions and facilitation of discussion, which were outstanding.

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**The Society's Annual Spring Conference and AGM will take place on Saturday, 26 April 2014 at Rock Townsend, The Old School, Exton Street, London SE1 8UE**

**Further details to come.**

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## Editor's Note

As I've been putting this edition together, it has made me more aware of the depth of the community to which we belong: at our third Neuroblastoma Research Symposium which we hosted in Liverpool last November it was very encouraging to see the number of junior researchers attending alongside more experienced colleagues; the gathering of patient advocates from across Europe sharing their experiences with clinicians and researchers; the collaboration between charities and individuals worldwide in the fight against neuroblastoma; and then there's you—our fundraisers—individuals who have been thrust into the world of 'neuroblastoma' through circumstances you would rather not have experienced but who have taken on the challenge of helping us beat this aggressive disease.

At the root of all this activity? Research. Research into finding the best treatments, new treatments, treatments that will ensure children with neuroblastoma will survive. That is what The Neuroblastoma Society will continue to focus on.

*Shirley Clark*

Have you been fundraising for The Neuroblastoma Society? Would you like to share your story? Please send contributions and photos (digital preferred) to the Editor at: [publicity@neuroblastoma.org.uk](mailto:publicity@neuroblastoma.org.uk)

Articles for the Spring Newsletter  
DEADLINE 28 February

## Neuroblastoma Research Symposium 2013—contd

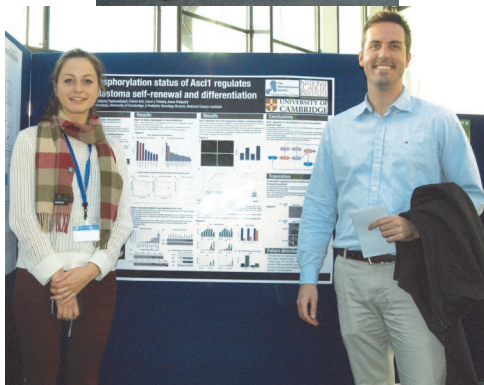
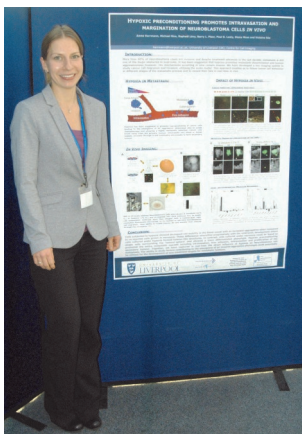
Secondly, junior researchers (Postgrads and Postdocs) made a major contribution to the meeting, with excellent posters and talks. That many contributed to the general discussion was testament to the relaxed and productive atmosphere of the meeting. Feedback was very positive, with one junior researcher writing: "People have approached me for collaborations and job opportunities. This interaction rarely happens in a big meeting." We hope that many will continue their careers in neuroblastoma research.

Congratulations to Anne Hermann (Liverpool) and Luke Wylie and Tatiana Papkovskaia (Cambridge) for being selected for poster prizes, kindly donated by SPARKS charity.

The third aspect that added great value to the proceedings was talks from the point of view of other childhood cancers. Steve Clifford (Newcastle) spoke interestingly about the lessons from MYC involvement in medulloblastoma tumours of the

cerebellum, while Suzanne Turner (Cambridge) introduced us to the successful deployment of mouse modeling of ALK mutations to test new drugs for Anaplastic Large Cell Lymphoma.

Now to a brief summary of the five themed sessions. The first focused on the MYC proteins that are the most common drivers of cancer, yet remain very difficult to inhibit clinically. Part of the reason for this is that they are master regulator proteins that activate the transcription of a huge number of downstream genes. Trying to work out which of these downstream factors are key to driving neuroblastoma and how they could be selectively interfered with was the focus of the first session. Two inhibitors of MYC-N were discussed, one targeting the Aurora Kinase A stabilisation of MYC-N, presented by Evon Poon (Sutton) and one destabilising the partnership between MYC-N and its partner protein MAX, presented by Marie Henriksson (Stockholm), both of



*(Continued on page 4)*

which have shown promise in mouse models.

It is now clear from the genetic profiling of neuroblastoma tumours that the disease is not driven by a handful of common gene mutations. As a result, profiling has so far added disappointingly little to the accuracy of disease prognosis. However, in the second session on the genetic landscape of neuroblastoma, Jo Vandesompele (Ghent) showed that an ultra-high-risk group of patients can be identified, for whom new treatment protocols are needed. In this session, Karim Malik (Bristol) spoke about targeting the epigenetic causes of neuroblastoma and Rosa Noguera (Valencia) about visualising the important sub-group of slow-burning but deadly tumours characterized by a loss of the long arm of chromosome 11.

Retinoic acid (RA) has been used for some time as differentiation therapy at the end of conventional treatment in an attempt to prompt any remaining tumour cells to become benign or die. In the fourth session Gareth Veal (Newcastle) showed that the effective uptake of RA by patients given similar doses varies greatly. Monitoring the effective uptake in blood plasma, and increasing dosage if there is poor uptake, leads to more consistent effective dosage. Though simple, this was a salutary lesson in the benefits of monitoring drug delivery. Andy Stoker (UCL) showed

that oxovanadium compounds act synergistically with RA, a theme that was echoed in the final session.

In the penultimate session, Laura Danielson (Sutton) provided an excellent general introduction to mouse models that are now routinely used to understand neuroblastoma biology and for the preclinical development of novel therapies. Transgenic mice with MYC-N over-expression or ALK mutations (or both) have already been used to prove preclinical efficacy of novel drugs that have gone on to clinical trial. In exciting new models, gene errors can be turned on and off through dietary control, and Juliet Gray (Southampton) reported on state of the art immune-competent mice suitable for studying immunotherapies. The benefits of using the cheaper zebrafish, *Xenopus* frog or fruit-fly models for some pre-clinical work were also discussed. Violaine See (Liverpool) showed how useful the chick model is for understanding and, remarkably, visualising the live process of neuroblastoma metastasis.

The meeting concluded with two refreshing talks (Marthe Howard, Toledo and Anna Philpott, Cambridge) on the detailed biology of two other master genes that are essential for the normal development of sympathetic neurons that, when things go wrong, give rise to neuroblastomas. Reactivating these master genes in



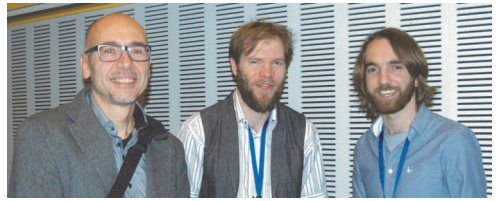
neuroblastoma cell lines encouraged cells to become benign or die. Exploiting the synergies of multiple differentiation therapies emerged as an under-exploited and promising route to improved treatments.

Thanks go to Shirley Clark for organising much of the Symposium, and to Yvonne Boyd and Deb Tweddle for help with the programme. Feedback from the Symposium has been excellent, and we hope to hold the next one in Newcastle in 2015. I am grateful to Emma Bell (Heidelberg), Lindi Chen (Newcastle) & Virginie Viprey (Bradford) who are contributing to a scientific write-up, a link to which will be advertised on our website.

Finally, I wanted to acknowledge a special characteristic of these Symposia, which is the contrast between the awfulness of the disease we are all focused on, and the warmth and collaborative nature of the community of scientists and clinicians who are trying to find better treatments. The latter is surely the best recipe for success, and The Society will do its best to continue to foster this.

*Guy Blanchard, Research Trustee*

*[And we also thank Guy Blanchard for not only initiating our series of Symposia but for his enthusiasm and dedication in making them happen.]*



**The European Cancer Congress 2013 was held in Amsterdam last September. Trustee, Susan Hay, attended the 'Patient Advocacy' sessions on behalf of the Neuroblastoma Society.**

This conference is huge! It brings together all the large umbrella cancer organisations across Europe to 'reinforce multidisciplinary' and was attended by thousands each day.

ESMO, ESTRO, ESSO, EACR, EONS and SIOPE were the founding members which created the ECCO Congress, whose programme now consists of 28 scientific frames and just under 4000 presentations. This year, the Patient Advocacy and Ethics track was awarded a central position and focussed on collaboration between health professionals and patients, and was supported by a Patient Advocacy Square, a dedicated exhibition area for cancer patient advocacy organisations including booths and a lounge area, providing an opportunity to promote their resources and services to the professional oncology community, and interact and exchange information with each other. Comments follow on just a few of the sessions I attended and the messages that I took away for effective patient advocacy.

**Best Practices: Advocacy – Didn't we do well? Jointly chaired by Geissler, J (Germany) and Erdem, S (Turkey)**

Charities working together to achieve a national cancer control strategy in Sweden, started by identifying the obstacles to reaching consensus:

- how to divide age groups
- drawbacks and benefits of available treatments
- competition for funds between organisations

differing political inclinations.

It was soon realised that an upcoming election was a critical moment to make real change and the charities working group surveyed all political parties specifically on the budget they were prepared to set aside for cancer, how best charities could support them in writing this part of their manifesto, and how each party would tackle regional differences. The group secured involvement in, and the commitment of, all parties and the following shift of government resulted in little option but to act on the promises made and to enlist the participation of the group on the development committee. This placed patient advocacy centre stage in cancer policy.

Ingrid Kossler, on behalf of the group,

noted that the work had required charities to agree a set of priorities and guidelines for putting forward their aims to

government, which had been challenging, for example, where there is no real evidence of efficacy, why should there be a demand for screening?

Ann Bogels from the Netherlands described how charities had joined forces to advocate for a standard for integrated care, to improve transparency within the care system with the aim of making the quality circle work – plan, do, check, act. The approach was to look at quality criteria from the patient perspective - making the quality of care visible to patients as a means of aiding choice. The result is an online system showing hospitals that meet the quality criteria, and in what way some do not. The system has earned the respect of hospitals and has improved care – from the patient’s perspective. In the case of intestinal cancer, the score has risen from 37% of criteria met, to 84% within 18 months. One of the most significant findings of the work has been that families are ready to travel considerable distances for better care. A related finding has been the importance attached to GP advice and follow up as the local conduit when treatment takes place elsewhere.

Cancer charities in Italy are more

concerned with the inclusion of employment rights for those in treatment and survivors in the national cancer plan. Already secured is that patients can reduce to part time, and resume full time work when they are ready. A cross-sector alliance is considered crucial to achievement, and their next goals are to negotiate a reduction in the time lapse before disability benefits are claimable to 15 days from the start of treatment, and to secure access to innovative drugs in all parts of the country.

Collaboration between charities and health professionals was stressed again by representatives of VOICE (UK), who have teamed with Barts Cancer Institute in London to run ‘Science for Advocates’ courses. Running over 5 days the courses provide an introduction to basic cancer biology and to research terminology and clinical trial design.

<http://independentcancerpatientsvoice.org.uk/voice-science-for-patient-advocates/>

### **Empowering Survivors of Childhood and Adolescent Cancer – Chaired by Pritchard-Jones, K (UK)**

The session was introduced with the statistic that 1 in 1000 childhood and adolescent cancer patients currently survive; two-thirds suffer severe complications in later life, for which up to a quarter are life-threatening. As survivorship increases, so should our attention to issues surrounding survivorship, the most important

being empowerment of the patient through good information and support, and the key obstacle being the lack of co-ordination and integration of services.

Several speakers noted the work of PANCARE, the Pan-European network for Survivors after Childhood and Adolescent Cancer, a multi-disciplinary group of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of cancer treatment. PANCARE's work has focussed on the collection of genetic information in combination with scientific risk factors, to provide stratified risk surveillance for patients. Through this work, survivors are beginning to drive a research agenda, which in turn should provide evidence for lobbying for change.

<http://www.pancare.eu/en/>

An initiative in the Netherlands has led to out-patient clinics specifically designed for adult survivors of childhood cancer. The clinics have responsibility for follow up counselling with patients and with health professionals, to identify frequency of and most effective testing within the guiding principles of early diagnosis and proper co-ordination of care. The International Guideline Harmonisation Group within PANCARE is working towards a European register of late effects.

A further initiative currently being

developed by PANCARE in association with ENCA (European Network of Cancer Research in Children and Adolescents) is a Survivorship Passport which will record the medical history of the patient to indicate the risk of late effects. The passport will specify what to do in the face of a specific symptom, and provide for the easy transfer of information between health professionals. As well as detecting late effects and taking action earlier, the passport will provide useful evidence in, for example, negotiating insurance by patients, and data for clinical trial and updating purposes – although this is likely to require a major investment in harmonised data collection.

Collaboration between patients and professionals was the overwhelming theme of the sessions I attended, and is at the heart of the success of many of the patient advocacy projects and initiatives discussed.

*Susan Hay, Trustee, Charity Liaison*



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# The Neuroblastoma Consortium



THE  
NEUROBLASTOMA  
CONSORTIUM

The Neuroblastoma Society is a member of The Neuroblastoma Consortium. This Consortium is an initiative spear-headed by US-based William Guy Forbeck Research Foundation and has been set up to facilitate collaboration between non-profit groups and individuals across the world whose mission is focused entirely or in part on accelerating effective treatments for neuroblastoma, or advocating and supporting those affected by the disease. Countries currently represented as well as the US, are the UK, Australia, Netherlands, Italy, and Canada.

Its three areas of focus, each supported by a committee of members, are

- Scientific and medical research
- Advocacy
- Family Foundation support

The Committees have identified their initial objectives as

Scientific and medical research:

- 1.Collating member entity neuroblastoma research funding information
- 2.Developing a neuroblastoma research impact plan

Advocacy:

- 1.Family support and education
- 2.International representation and networking

Family Foundation support:

- 1.Sharing operational models and best practices
- 2.Offer resources for other new and emerging foundations
- 3.Sharing and consolidation of resources.

A Medical Advisory Board is currently being established and a Consortium website has just gone live:

[www.neuroblastomaconsortium.org](http://www.neuroblastomaconsortium.org)

The Consortium meets quarterly by conference call. Its first in-person meeting will be held at the ANR meeting in Cologne in June 2014.

*Susan Hay, Trustee, Charity Liaison*

**Did you know you can set up a regular donation to the Society through JustGiving.  
[www.justgiving.com/nsoc/Donate](http://www.justgiving.com/nsoc/Donate)  
Help us fund more neuroblastoma research**

# The Alphabet of Fundraising—Part 3, Q-Z

*Based on a presentation at the Society's AGM in April 2013:*

This is the last instalment of our round-up of some of the fundraising activity which our supporters have been doing over the past year or so to raise funds for the Society. The applications for grants, from researchers around the country, are being submitted to us round about now, and we'd love to fund as many of the best projects as possible – and of course that is only possible by the amazing range of fundraising activity which the Society's supporters get involved in. Wondering if we've got an X, Y and Z? Read on...

**Q – Quiz.** Always popular fundraisers as they add the social (and competitive) element. Our Fundraising Pack contains all the ingredients you need to host your own pub quiz (including the questions, and answers) – just email Natalie to request one

**R – Running.** A good percentage of our income each year comes from sponsored running events. The showcase event is the London Marathon, with 11 brave runners doing it for the Society last April, and the Great North Run and Great South Run are also popular. Our supporters run every distance, all over the country, and the Society can often get charity places in the big events, as well as supplying running vests and other

valuable aids (not spare legs or lungs unfortunately). Contact Sue Davies for more details.

**S – Selling.** From hand-made jewellery to chopped firewood to model buses to hand-knitted scarves – people are happy to give to the Society if they get something in return. As well as these home-produced items, you can also donate a percentage of any item sold on e-bay to the Society, it's as simple as a click of the mouse.

**T – Tombola.** I'd include Raffles as well but we already have an R – again, people are always happy to give if there's a chance of winning something, so if you can get your hands on some prizes, and have access to a few willing punters, that's a great way to raise funds.

**U – Unwanted toy sale.** One family we knew couldn't actually get into their garage for all the toys in there, most of which their three children had grown out of. So they had a big sale, sold the lot and gave the proceeds to the Society. And got their garage back.

**V – Village party.** Like any big party or ball, this takes a bit of planning and organising, but back in December a whole village in Hertfordshire had a fantastic evening in their village hall with a home-grown band, home-produced food, and of course a well-stocked bar. Another great event was a Winter Ball last year, organised by

one of our supportive families. Nights to remember, and great for raising funds, and awareness, for the Society.

W – Walking. As with the running events, we get quite a few people undertaking walks to raise money for the charity – destinations over the past couple of years have included the Great Wall of China, to Hadrian’s Wall, and just around the local park. And doing it in the bright yellow Society t-shirt certainly gets you noticed. When two or more are wearing one, it’s not just the Great Wall of China that is visible from outer space.

X – Xmas Cards. The Society has its own range of Christmas cards for sale. Alternatively, and something we’re benefitting from more and more, people deciding not to send Christmas cards to everyone they know, but to give a donation to the Society instead.

X – Cross-Channel Swim. A heroic effort by a team of Society supporters last year – and an opportunity for me to put two items under X.

Y – Yoga. A yoga instructor, who knew the family of a neuroblastoma patient, decided to raise funds by holding a free introductory yoga session, with donations to the Society. Now that’s something to meditate on.

Z – Zumba! Thank goodness, a zumba teacher held a free session on the morning of her village fete this summer, with donations to the Society and a discount off the following term’s session to anyone who donated. Great

village exercise, great marketing for the zumba teacher, great donation made to the Society. And it provided me with a Z.

They are all true! I’m sure we’ve missed some – really sorry if we have missed yours out, do tell us about it - but we have included loads of fantastic ideas and stories behind the fundraising in the last three editions of this newsletter. Hopefully some of these will give you, or your friends, some ideas on different and fun ways to raise money for the Society. Meanwhile we’d love to hear what fundraising ideas you have, or activities you are planning. We will support them in any way we can – we can provide fundraising packs, banners, t-shirts, balloons, information sheets, help and advice - just contact Natalie on [fundraising@neuroblastoma.org.uk](mailto:fundraising@neuroblastoma.org.uk)

***Ben Sharp, Trustee***

**Secure your place now!**  
[sports@neuroblastoma.org.uk](mailto:sports@neuroblastoma.org.uk)

## Alex's Story

We were contacted last year by Alex Clarke who was interested in taking part in the Virgin Money London Marathon to raise funds for the Society and wondered whether we could offer him a place. Happily, we were able to oblige and this is the reason for Alex's motivation.

In January 1993, I was diagnosed with neuroblastoma, an aggressive form of childhood cancer which forms in the abdomen (in my case, on my right adrenal gland). Luckily, it was caught just in time and was still treatable. Over the next nine months, I underwent major surgery to remove the tumour (a melon-sized lump in a not-many-melons-sized toddler), several courses of intensive chemotherapy and a bone marrow transplant to kill the spreading cancerous cells. Thankfully, the treatment was a success and I was finally pronounced cured in 2010 after many years of long-term remission. I'm here today to run my legs off in an effort to repay the many dedicated and talented people who saved my life.

Unfortunately, not everyone is as lucky as I've been. The majority of children diagnosed with neuroblastoma in the UK each year fall into the high-risk category, for which the survival rate is less than 40%. Hopefully, by funding research carried out by charities such as The Neuroblastoma Society, we can give more of them the chance they deserve to live a real life.

*We are hugely grateful to Alex for taking on this challenge and for sharing his story. If you would like to support him, please visit his fundraising page:*

*<http://www.justgiving.com/fighting-childhood-cancer>*



## A Fresh New Look

With a new batch of Trustees having joined our Board in the last 18 months, and exciting new research on-going which we are helping to fund, it was decided that The Neuroblastoma Society logo needed a refresh to bring the Society's image more in line with its activities.

A graphic designer was appointed, Jane Walsh of Eight Creative,

who very generously donated her time to develop our new logo so no expense was incurred.

Jane came up with a number of concepts and, after much discussion, Trustees agreed on this design.

It was felt the branding of The Neuroblastoma Society should be simple and bold, enabling it to stand out on t-shirts, vests, banners and balloons for fundraising events, but also to relate to research, which is the area where we excel—we are one of the leaders in neuroblastoma research funding in the UK.

The new branding clearly retains the parent and child aspect of our support for neuroblastoma families but the figures are representative of chromosomes, demonstrating the research and science element to the Society.



**THE  
NEUROBLASTOMA  
SOCIETY**  
FIGHTING CHILDHOOD CANCER

We felt it was important to stay with our existing two shades of blue for brand recognition, but we have also incorporated yellow or gold as this colour is used for our t-shirts and is also the colour recognised for childhood cancer awareness.

We will be introducing the new logo during the next few months and it will be running

alongside our existing design for a short time during the transition. If you are organising an event shortly and would like to use the new logo, we do have specific brand guidelines which we would ask you to follow—please get in touch and we'll let you have details.

We are also currently working very hard on developing a new website, and we hope this will be ready shortly. This will incorporate the new branding, as well as new areas of information, research and an online shop, as well as news on fundraising activities. We hope the new website will be more interactive and friendly to use for parents, relatives, children and fundraisers.

*Tori Oldridge, Trustee, Media & Web*



### Table Top Sale

Mrs Sara Coleman from Gimingham, near Norwich, sent the Society proceeds from a coffee morning and table top sale by Barrington Farm Project of The Rookery in Walcott in memory of Ryan who recently lost his fight with neuroblastoma. Thank you to all at the Future Factor Group for making the various products available at your fundraising event!

### The Long & Short of it

Sarah Keary from Co. Galway, but studying and living in Germany, was inspired by Lily-Mae Morrison's fight with neuroblastoma and decided to raise money for research. On the eve of her 24<sup>th</sup> Birthday Sarah shaved her head and with the help of all her family and friends raised €1,080 for the Society. Thank you Sarah!

### Cake Sale

Two Year 8 students from Wyvern College in Hampshire, Libby Haskell and Chloe McCormick organised a cake stall in memory of Libby's cousin, Alex Blair, and raised a wonderful amount for the Society. The homemade cakes were truly scrumptious and extremely popular.

A big thank you to all students and staff at the college for their support.

### Model Buses

Buses come in all shapes and sizes but Xelabus has gone the extra mile and reproduced models of its own fleet.

The latest, a model of a college bus that operates for Itchen College in Southampton has recently hit the streets for model collectors.

Gareth Blair, Operations Director of Xelabus said "We do get many requests for models or pictures of our buses. Last year we produced a model of one of our single decker vehicles which sold very well. This year we hope this model will be equally as popular." £5 from all the models sold will be donated to The Neuroblastoma Society in memory of Alex Blair who lost his battle in 2009 to neuroblastoma.

The latest model a Double Deck bus showing 192 Itchen College is being offered only being available from Xelabus at Eastleigh by calling 02380 644715 or emailing [gareth@xelabus.info](mailto:gareth@xelabus.info)

### A Christmas Carol

Our thanks to Lynne Austin-Dutton from the Voice Studio and her students who dressed in Dickensian costumes and sang carols round their neighbourhood raising £670 for the Society.



Clockwise from top left: Sarah Keary losing her hair; the Barrington Farm Project sale; Steve Perkins the Assistant Principal for Itchen College and Gareth Blair; Wyvern College cake sale; Lynne Austin-Dutton and students; Room 21 Big Band and Kerry Strong's 40s night



## Walking Stars, Auckland

On the other side of the world, when they should have been sleeping, Sarah and her friends went for a walk. Not just any walk but the Walking Stars half marathon in Auckland. Sarah has raised a fabulous amount for neuroblastoma research in memory of Lizzy B. Thank you Sarah!



## London to Paris Cycle Ride

In 2004, following her cousin Molly's diagnosis with neuroblastoma, Michelle cycled from John O'Groats to Land's End in support of the Society. Ten years later, Molly is 12 and Michelle is off again! This time she is cycling from London to Paris to support our work. As one of her fundraising events, Michelle bravely lost her locks—thank you!



## Riley's Challenge

In our last newsletter, we wrote about GP Dr Simon Cooke's challenge of cycling from Innsbruck to Salzburg to raise funds for neuroblastoma research after one of his young patients was diagnosed with neuroblastoma. Dr Cooke also had a surgery open day and here he is along with Riley and his mum, with a cheque for the Society. Our thanks to Dr Cooke and best wishes to Riley and his family.



## Lizzy's Legacy

We were saddened to hear that little Lizzy Bremer had lost her battle against neuroblastoma in the summer. The Bremer family and friends have been fundraising for neuroblastoma research in her memory and we are very grateful for everything they are doing for the Society. Visit <http://lizzy.bremer.co.uk/> for more information.

## Christmas Cards

A big thank you to everyone who bought Society Christmas cards last year. Sales were down on the previous year but we were still able to put a wonderful amount towards neuroblastoma research.

Thanks to Lucy Bailie, Maureen Stevenson and Frank Townley for their efficient organisation in supplying and distributing the cards.

Next year, as well as ordering by post, we're hoping that you will be able to order on-line through our new website! Watch this space.

## Smile with Siddy

Smile with Siddy, a Bristol based charity, has been collecting used stamps for our stamp appeal—thank you guys!



The charity was set up in memory of Siddy Cahill who sadly died from neuroblastoma in January 2013 and they raise money to increase awareness and fund research and treatment of neuroblastoma. They are currently updating their website (us too!) but you can find out more on their Facebook page.

Used stamps—little bits of wasted paper—are easy to collect and can be profitable for us! Send them to Mr & Mrs Wade—details on back page—foreign and picture stamps preferred. Thank you!

## BADA Gala Reception

*Lizzy's Legacy have organised this fantastic fundraising event.*

We are thrilled to announce that tickets are now available for our Charity Gala Reception in Lizzy B's name at the opening night of the British Antiques Dealers Association (BADA) Fair on March 19th, 2014, raising funds for research through The Neuroblastoma Society.

Tickets are £60 each and include:

- entry to the fine art and antiques fair PLUS re-entry on a subsequent day
- the BADA handbook
- entry to the Gala Reception
- drinks and canapes provided by 'Absolute Taste'
- goody bag with lots of 'goodies' - including a custom made Lizzy pink cashmere pashmina designed for our event and made by 'Rumah, London'

We have some incredible auction and raffle prizes which include Guess items, beauty creams, yoga dvds, signed sporting stuff, VIP to the V-Festival, Royal Opera House private box tickets, dinners, hotel stays, Brands Hatch track day, Eurostar tickets with 2 night stay in Paris - wow, the list goes on!

Book your tickets by visiting <http://lizzy.bremer.co.uk/>



2013 has been a bumper year not only for our normal events but also for individual challenges. Our last newsletter covered many of these from mountain toppers to towpath trotters, not forgetting the two-wheelers and mountaineer-ers. You have been amazing. And so to 2014!

We've already filled our places in the London and Brighton Marathons in April but we can still offer an amazing new challenge—the London Triathlon in August! If you fancy something a little less strenuous we are looking for participants in the British Lion 10k in July too.

We always welcome your own athletic efforts as well and we can supply you with a fundraising pack and a t-shirt or vest so you can show who you are raising money for. It's great to hear about fundraisers young and old and inbetweenies.

Looking further ahead we are hoping that we can secure places for the Ride London in 2015. Meanwhile we wish Michelle Jones good luck in her personal challenge, the London to Paris Ride in April 2014. She's been raising funds by having her head shaved!

We are also looking forward to the Brentwood Half Marathon in March with over 200 runners running for Lily's Legends. Thanks to Emma

Ambrose who has been busy organising pre-event fundraisers for this including a pamper evening. This will surely be an a-mazing event for sheer weight of numbers and anyone in the area should get down there and give them a wave. (Now there is just the matter of getting Santa's elves to make 200 shirts in time...)

We also remember that many of you take on these challenges for personal reasons. We've had 500 for Alex organised by Chris Noble in memory of his son and also Miriam Bremer has quietly been getting on with running in as many events as possible in tribute to her daughter Lizzy. We know that all of you have been touched in some way by the disease and you respond in such a positive way.

Now remember we love you raising money online but sometimes unless you blow your own trumpet we might not get the chance to thank you. This organisation is all run by volunteers and although we try to ensure we do get around to everybody sometimes you slip under the radar. So get on Facebook with your photos. Tweet us and email us. We love to hear from you so we can include it in the newsletter as well.

*Sue Davies*  
*Sports Organiser*  
*sports@neuroblastoma.org.uk*



## Coast to Coast

We're very grateful to Paul Kinnersley who completed the coast to coast cycle ride (Workington to Sunderland) in September, raising a fantastic amount for neuroblastoma research, in memory of Jasmine Yearsley. Paul tells us:

*Hi to all who aided in making this happen, especially KMF who did the back up, we had two minibuses following all the way. I must admit the last day was a tester as I cracked a rib after falling with about another 40 miles to do. With the help of some pain killers, I completed the course. Again thank you to all who donated in aid of Jasmine and this Charity.*




## Three Peaks Challenge


Christopher Coates is taking on the Three Peaks Challenge in June in memory of his brave and beautiful daughter, Charlotte Rose, who passed away from neuroblastoma in 2006. We wish you every success, Chris and thank you for your support.  
[www.justgiving.com/Chris-Coates514](http://www.justgiving.com/Chris-Coates514)




# SUPPORT JACK AND THE NEUROBLASTOMA SOCIETY



The Neuroblastoma Society  
Fighting Childhood Cancer  
[www.nsoc.co.uk](http://www.nsoc.co.uk)  
Registered Charity No. 326385



## LONDON MARATHON 2014



I'M RUNNING MY FIRST MARATHON IN MEMORY OF MY COUSIN HALEY WHO PASSED AWAY JUST BEFORE HER SIXTH BIRTHDAY DUE TO THIS RARE CHILDHOOD CANCER. PLEASE SUPPORT THIS GREAT CAUSE BY DONATING ONLINE TO MY JUSTGIVING PAGE OR CONTACT ME [JACK@PBDLTD.CO.UK](mailto:JACK@PBDLTD.CO.UK) THANK YOU :)

[WWW.JUSTGIVING.COM/JACK-ALLEN5](http://WWW.JUSTGIVING.COM/JACK-ALLEN5)

## The White Ring

"With 22 kilometres of piste and 5,500 metres of altitude, 'The White Ring – The Race' [between Lech and Zürs in Austria] is the longest ski race in the world according to the Guinness Book of Records." This was Justin Marsham's challenge in January in memory of Lizzy B. He came back unscathed thankfully and having raised a substantial amount for neuroblastoma research—thank you!



## Donations

**Thank you for all donations received by the Society. Every single one makes a difference.**

*Kathryn Mcdermott* from Co.Durham, sponsorship collected for their daughter Laura's Great North Run.

*Mrs Joan Downes*, on behalf of the *Bristol Masonic Charities*, in memory of her great grand daughter, Raphaella Poppy Moggridge.

*International Financial Data Services* from Essex, money raised by the IFDS staff during a recent "dress down" Friday.

*Margaret McLaughlan* from Lanarkshire, a donation from her employer, *Ernst & Young*, to match some of her fundraising.

*Monica Robinson* from Northwich, in memory of Imogen Mia Bates.

*Mrs Dawn Muggridge* from Thetford, numerous donations from family, friends and campers at the Camping and Caravanning Club, received in lieu of flowers in memory of her husband, Rob Muggridge, who died in a tragic accident on 13<sup>th</sup> July, and in memory of her daughter, Chloe Peaches, who died 10 years ago.

*The Phoenix International Charity* from London, accepted *Jane Horn's* nomination of the Society as a recipient of one of their charitable donations.

*Caleta Hotel* from Gibraltar, to support the Society's work.

*The Rotary Club of Leatherhead* from Surrey, a donation to the Society following a talk to the Club by Jemma Purvis.

*Trudi Eden*, landlady at Miller's Bar, Sittingbourne, content of a collection box at Miller's Bar, a donation from *James Dunnage* - proceeds from his sponsored head shave, money raised by *Chris Ewell* and including a donation from *Dalbir Hayre of Structural Weld & Testing*.

*Ben Sharp*, numerous donations comprising of:- sponsorship money for the charity bike ride (Raid Pyrenean) by *Matt Aldridge* et al in July; proceeds from the sale of firewood by Ben; sponsorship money for Ben's daughter, Jennifer, cycle ride; a collection by *Little Chalfont Brownies*; a donation in lieu of presents for Jennifer's Birthday.

*Mr and Mrs Nicholas* from Port Talbot, in memory of their grandson, Rhys, who died of neuroblastoma on 30<sup>th</sup> September, 1992.

*Will Garrett* from Newcastle Upon Tyne, offline donations received in support of his Coast to Coast bike ride on 20<sup>th</sup> July.

*Miriam Bremer*, off line donation from *Mackintosh Foundation* in support of Miriam's fundraising efforts.

A donation from *Miss W H S Wallace's Settlement Trust* as agreed by the Trust's trustees.

*Nicky Slater*, to support the Society's work.

*St Leonard Lodge* No 4982 from Essex, in support of Mrs Kerry Richardson for running for the team "Lily's Legends" in aid of the Society.

*Mr David Battle* of Lorica, proceeds from their annual golf day.

*Mr & Mrs Peters* from Great Wakering, in memory of their grandson, Tom Willson – a donation to the Society in lieu of a payment for a piece of furniture to a neighbour.

*Elaine Lindup* from St Helens, money raised by Ryan Coleman who completed a skydive this year in memory of Elaine's daughter, Ruby Lindup, who passed away in December 2008 with stage 4 neuroblastoma. Also, a donation from *Brenda Parr*, in memory of her mother, Agnes Rowlands, who passed away in 2013 and in memory of Ruby Lindup.

*J M Harrison* from Derbyshire, content of a collection box.

*Tori Oldridge of Bounce PR*, a donation from a work colleague to support the Society's work.

*Mr Geoff Austin* from Rye, money raised by the family over the past year in memory of his granddaughter, Gemma Sharpe, who died while undergoing treatment for neuroblastoma on 19<sup>th</sup> June 2007, aged 3 years and 10 months.

*Lorica Employee Benefits* from Hampshire, further proceeds from their 5<sup>th</sup> Annual Golf Day.

*Mr & Mrs Clark* from Swanage, donations received in lieu of presents for their Ruby Wedding Anniversary and given in memory of Benjie Stafford who died on 19<sup>th</sup> May 1988, aged 4 years.

*Janet and Colin Dobson* from Christchurch, in lieu of buying the Society's Christmas cards and in memory of their beautiful granddaughter, Kassie, who sadly died on 29<sup>th</sup> January 2011, aged 22 months.

*Mrs Maureen Anderson* from Reading, in lieu of buying the Society's Christmas cards.

*Michael and Caroline Gray* from Haddenham, offline donations received in memory of their youngest daughter, Lily Gray, who passed away on 19<sup>th</sup> September. Numerous donations have been received through a page set up in memory of Lily: [www.justgiving.com/LilyGray](http://www.justgiving.com/LilyGray)

*Miss D L Hardy*, in memory of Jim Davies.

*J & J Walling* from Reading, in memory of Frederick James Davies who died on October 19<sup>th</sup>.

*Mr John Ricketts* from Cheltenham, in memory of his friend and fellow Cotswold Humanist, Frederick James Davies.

*The Lighthouse Nursery School* from Newington, proceeds from their charity event on 29<sup>th</sup> August in support of the Society's research fund.

*Lorraine Hall* from High Wycombe, proceeds from an annual quiz held at Flackwell Heath FC in High Wycombe in memory of her son, Jake Hall, who would have been 21 in September. Thank you to Tracy who was a superb Quiz Master again and to everyone who supported the event.

*Dr Simon Cooke* from Norwich, sponsorship money from his patients for completing Austrian Challenge 2013 cycle ride in May in aid of the Society and money raised by the family of his first neuroblastoma patient, Riley.

*Mr Kevin Murphy* from London, in memory of his beloved grandson, Michael O'Donnell who passed away in March 2006 and Michael's beloved Nanny, Eileen, who passed away in August 2013.

*Mrs D M Carley* from Dover, in memory of a dear friend, Frederick James Davies, who passed away on 19<sup>th</sup> October.

*IT Performs Ltd* from Sutton Coldfield, in support of the Society's work as requested by Chris Yearsley at PDSA.

*Stratford-on-Avon District Council*, to support the Society's work.

*Class 5W from Ysgol Penmorfa, Prestatyn*, proceeds from a cake stall.

*Mrs Sheila Walker* from Knaresborough, in memory of Mr FJ Davies.

*Danny O'Donnell* from London, a donation from his employer in memory of Danny's beautiful son, Michael O'Donnell, who died in March 2006 aged 8.

*Margaret Beech of BT Women's Network*, North West, a donation following the closure of their account. Margaret's son, Steven, was treated for neuroblastoma in infancy and now at the age of 34 is doing really well. Sadly, Margaret's friend's daughter, Michelle, who lived in the same village and was also treated for neuroblastoma, passed away at the age of 9.

*A J & D A Huck*, in memory of Jim Davies.

*Christ the Redeemer Parish Church from Southall*, half of the collection taken at their Annual Memorial Service. Father Nigel Orchard's nephew was diagnosed with neuroblastoma about six months ago and has recently been given the all clear.

*Mrs Kerry Strong* from Scunthorpe, proceeds from the Fabulous 40s Night with Room 21 and Pyramid Disco at Redbourn Club in honour of her nephew, Alexander Strong, who sadly passed away in January 2013.

*Ben Sharp*, further donations from:- *Citygate* - local car dealership following a Village Day in his home village of Little Chalfont, Bucks; sponsorship for *Robert Higgins* who cycled the Grand Union Canal in July ([www.virginmoneygiving.com/team/robandrobb](http://www.virginmoneygiving.com/team/robandrobb)) and including donations from *W H Carden Ltd*, *Mr & Mrs Sharp* and *Anthony Caparn*; sponsorship for Ben's daughter's cycle ride in September; donation from *Mr AG Sharp*, Ben's father; donation from *Little Chalfont Community Association* - proceeds of a Fun Run and dog show at the Village Day.

*Julia Stevenson* from Crawley, proceeds from a craft sale organised along with a friend of the Matthew Russo Foundation and a personal donation in memory of Julia's son, Ben Stevenson, who sadly lost his neuroblastoma battle in 2007 aged 3.

*Mrs A N Hogman* from East Grinstead, to support the Society's work.

*Gillian and Wayne Taylor* from Chester-le-Street, Great North Run offline sponsorship.

*Mrs A Adams* from Romford, in support of Lily's Legends and the Society's work.

*Wincham Community Primary School*, proceeds from a competition held by Finbar Callaghan.

*Mrs Shelagh Barker* from York, in memory of Jamie Inglis.

*Mrs Val Weaver* from Bexleyheath whose son is a neuroblastoma survivor, proceeds from a Stand up to Cancer night held by her friend Lynn Haddon.

*Christ the Redeemer Parish Church, Southall*, donations by members of a bowls group in lieu of Christmas cards and token presents in support of Father Nigel Orchard's nephew who has recently finished his treatment for NB.

*Robin Dray* from Rayleigh, proceeds of a raffle held at a recent Chairman's Dinner.

*Michael and Anita Fielder* from Eastleigh, in memory of their darling Grandson, Alex Blair, who lost his brave battle with neuroblastoma in August 2009 aged 3.

*Mrs Margaret Sutherland* from Glasgow, donations and money raised from the sale of quizzes and the stall held at the Glasgow Charities day.

*Debbie Beevor* from Hatfield, in memory of her daughter, Hayley O'Brian, who lost her fight against neuroblastoma in 1993. Thank you to Debbie and family & friends for their 21<sup>st</sup> year of marshalling at St Albans Half Marathon.

*Chris Ewell* from Sittingbourne, proceeds from recycling aluminium cans, content of a collection box at Miller's Bar in Sittingbourne and proceeds from the sale of scrap metal to APM Metals.

*Nant Hall Road Presbyterian Church* in Prestatyn, from the children of the Sunday school to support the Society's work.

Sponsorship for *Jeanette Wright* from the Bournemouth Half Marathon

*Parish church of King's Sutton*, Northamptonshire towards the work of the Society.

**If you would like to contribute to our work, please send donations to:**

The Accounting Officer  
49 St Asaph Road, Dyserth, Rhyl,  
Denbighshire, LL18 6HG

**Cheques payable to:**  
*The Neuroblastoma Society*

**THANK YOU!**

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**Help us fund neuroblastoma research—  
make a donation today**



<https://mydonate.bt.com/charities/theneuroblastomasociety>



## The Origins and Aims of the Society

The Neuroblastoma Society was founded in 1982 by the parents and friends of five year old Matthew Oldridge who was dying from neuroblastoma. The purpose of the Society is threefold:

1. to raise funds for research into the disease to improve both its diagnosis and treatment;
2. to offer the opportunity for parents and friends to give each other mutual help, support and comfort;
3. to inform parents and supporters on the latest treatments and any medical advances relevant to the disease through our quarterly newsletter.

The Society is administered by Trustees, all of whom are unpaid volunteers. This means that around 95% of your donations to the Society go directly to fund research into neuroblastoma. We welcome help with all aspects of the Society's work. If you would like to be involved, please contact the Chairman, Steve Smith, by email at [chairman@neuroblastoma.org.uk](mailto:chairman@neuroblastoma.org.uk) or by phone on 01904 633744, for an informal chat.

### OUR HELPERS

<b>Annual Draw</b>	Mrs Tori Oldridge— <a href="mailto:annualdraw@neuroblastoma.org.uk">annualdraw@neuroblastoma.org.uk</a>
<b>Befriending</b>	Mrs Caroline Nicolaides— <a href="mailto:befriending@neuroblastoma.org.uk">befriending@neuroblastoma.org.uk</a>
<b>Collecting Boxes</b>	Mrs Sue Davies— <a href="mailto:collectingboxes@neuroblastoma.org.uk">collectingboxes@neuroblastoma.org.uk</a>
<b>Donations</b>	Mrs Wanda Davies, Accounting Officer, 49 St Asaph Road, Dyserth, Rhyl, Denbighshire, LL18 6HG <a href="mailto:donations@neuroblastoma.org.uk">donations@neuroblastoma.org.uk</a>
<b>Monthly Draw Club</b>	Mrs Anna Beecroft
<b>Newsletter Packers</b>	Mrs Maureen Stevenson & Mr Frank Townley
<b>Parents' Booklet</b>	Mrs Eileen Rowe— <a href="mailto:parentsbooklet@neuroblastoma.org.uk">parentsbooklet@neuroblastoma.org.uk</a>
<b>Pin Badges</b>	Mrs Mary Waterhouse— <a href="mailto:pinbadges@neuroblastoma.org.uk">pinbadges@neuroblastoma.org.uk</a>
<b>Sports Events</b>	Mrs Sue Davies— <a href="mailto:sports@neuroblastoma.org.uk">sports@neuroblastoma.org.uk</a>
<b>Stamp Appeal</b>	Mr & Mrs C Wade, 13 Longacre Road, Crossing, Braintree, Essex, CM77 8HG
<b>Website Co-ordination</b>	Mrs Tori Oldridge— <a href="mailto:media@neuroblastoma.org.uk">media@neuroblastoma.org.uk</a>

**SOCIETY HELP LINE**  
**FOR INFORMATION AND GENERAL ENQUIRIES**

**020 8940 4353**

**[www.neuroblastoma.org.uk](http://www.neuroblastoma.org.uk)**

