£1,000,000 TO FUND NEUROBLASTOMA RESEARCH THANKS TO CHARITY COLLABORATION

In early May the Society’s Scientific Advisory Board met to consider 17 research applications. The applications had already been reviewed by several scientific experts and the applicants had been given the opportunity to respond to any comments made on their proposals. The Board, chaired by Professor Kathy Pritchard-Jones, carefully considered all the information and discussed each grant in turn before coming to an agreed position on which proposals to recommend for support from the Society.

At the end of May, the Trustees of the Society met to discuss the recommendations of the Board and to consider how best to allocate the funds available. Thanks to collaboration with several other charities willing to fund neuroblastoma research – Action Medical Research, Niamh’s Next Step and Smile with Siddy – the Trustees were able to support research worth over £1 million and further discussion is underway with another charity which may enable additional studies to be supported. Co-operation with other charities is a significant step forward in making sure much-needed neuroblastoma research is funded.

The Trustees considered the awards for their scientific merit, benefit to neuroblastoma patients, value for money and their added value to the

(Continued on page 3)
Editor’s Note

With a little help from our friends, we have done it! This grant round has seen us able to fund more than £1mn of neuroblastoma research—an achievement well worth a pat on the back. And that, of course, includes you. Without your efforts, none of this would be possible—so THANK YOU!

We report on the Advances in Neuroblastoma Research conference held in Cologne bringing you the highlights from this biennial worldwide meeting of neuroblastoma experts. And we have a report on the International Confederation of Childhood Cancer Parent Organisations (ICCCPO) meeting in Valencia.

Following a review of Trustee roles, the Trustees are pleased to announce that Susan Hay has taken on the position of Chair, Steve Smith will become the Trustee responsible for health community and family liaison and Shirley Clark will be our Secretary. Natalie Cramp stood down as a Trustee and we send her our thanks and best wishes.
Society’s current research portfolio. After careful deliberation, the following grants (in alphabetical order of the main applicant’s surname) have been awarded either entirely or co-funded with another charity:

- **Louis Chesler** for his study on “Therapeutic Inhibition of MYCN – discovery and targeting of novel MYCN-binding proteins in neuroblastoma” to be carried out at the Institute of Cancer Research, Royal Marsden Hospital.

- **Robert Mairs, Colin Rae and Mark Gaze** for their study on “177Lu-DOTATATE combined with radiosensitisers to enhance targeted radiotherapy of neuroblastoma” to be carried out at the University of Glasgow. This work is co-funded with Action Medical Research.

- **Karim Malik, David Matthews and Sebastian Oltean** for their study on “A novel target for destabilization of the MYCN oncoprotein” to be carried out at the University of Bristol. This work will be co-funded with Smile with Siddy.

- **Anna Philpott and Louis Chesler** for their study on “Therapeutic use of kinase inhibitors to reactivate neuroblastoma differentiation” to be carried out at the University of Cambridge.

- **Violaine See, Diana Moss, Paul Losty and Barry Pizer** for their study on “Advanced in vivo imaging and transcriptomic analysis of neuroblastoma metastasis in a chick embryo model” to be carried out at the University of Liverpool.

- **Deborah Tweddle and Lindi Chen** for their study on “Preclinical testing of combinations of new therapies which target the genetic defects present in neuroblastoma”. This work will be co-funded with Niamh’s Next Step.

These awards cover a wide range of studies with the aim of improving the outcome for neuroblastoma patients. They include studies to understand how tumours spread or can be induced to differentiate as well as studies to improve current therapies and different approaches to controlling MYCN.

A further two awards are currently being negotiated and full details of these and the awards listed above will appear shortly on the website and in the next Newsletter.

*Yvonne Boyd, Grants Trustee*
The Advances in Neuroblastoma Research (ANR) 2014 meeting was held in Cologne on 13-16th May. This is a biennial world-wide meeting for neuroblastoma researchers and those involved in clinical trials, well attended by groups from around the world. First I will report on recent immunotherapy trial results, before picking highlights of what was new from the research presented in 100 talks and a few hundred posters.

Updates were presented from the Phase III high-risk trials from Europe (SIOPEN) and North America (COG). Alice Yu (San Diego) reported that event-free survival (EFS, meaning no relapses) in the COG study worsened from 3 to 5 years after treatment for the children who had received anti-GD2 immunotherapy with IL2 and GM-CSF, to the point where at 5 years there is no significant difference in EFS between these children and those who had had no immunotherapy. In the SIOPEN immunotherapy randomisation comparing anti-GD2 with and without IL2, Ruth Ladenstein (Vienna) reported that 3-year EFS was not different in the two trial arms, and that both were very similar to the EFS of the immunotherapy arm of the COG trial. However, significant pain and other side-effects meant that children on the IL2 arm often did not complete the full treatment regimen, and there was a suggestion in the data that if prolonged IL-2 could be administered with fewer side-effects, then there might be an EFS advantage to using IL2. So a new immunotherapy randomisation is planned including continuous infusion, based largely on research and early phase trial results driven by Holger Lode (Greifswald).

The working conclusion of all the above is that anti-GD2 immunotherapy is having a beneficial effect for a number of years, though this now needs to be converted into permanent benefit through improvements to the immunotherapy treatment, maybe alongside other treatments and over longer periods. GM-CSF appears not to be critical, and immunotherapy is thought to be particularly good at clearing bone-marrow disease. Promising variants on current immunotherapies were also being developed.

Kate Matthay (California) presented results from the first trial for OMS patients (often associated with ‘dancing eyes syndrome’), a debilitating neurological condition that often co-occurs with neuroblastoma and is likely to be an autoimmune condition targeting the child’s nervous tissue.

A large proportion of the talks at the meeting were about how to target MYCN-amplified disease. There were various talks on ways of targeting the...
MYCN-MDM2-p53 axis, with Aurora-A particularly targeted, while EZH2 is clearly critical to the epigenetic regulation of MYCN. CHD5 and LM01 were also promising targets with candidate drugs, amongst many others. It is impossible to predict which will make it into the clinic, but there is no shortage of candidates. As ever however, very few talks were focused on non-MYCN high-risk disease, often characterized by the loss of the short arm of chromosome 11 (11q- disease).

Progress on anti-ALK therapies continues apace, particularly by Yael Mossé and co-workers (Philadelphia). The crystal structure of the ALK protein is now known, revealing an important kinase domain where all the known ALK mutations are clustered. The drug Crizotinib binds to this domain interfering with ALK function, but how well it binds depends on the type of ALK mutation, something that is now understood at a structural molecular level. It is hoped new drugs can be engineered, similar to Crizotinib, which will interfere with all the different ALK mutations. Mossé has also been screening other drugs for synergies with Crizotinib and has homed in on CDK inhibitors as being most potent, though the mechanism of synergy remains elusive.

There were various updates on the genetic and epigenetic differences between tumour and normal host cells. Shahab Asgharzadeh (Los Angeles) showed how high-risk neuroblastomas can be split into neural, metabolic and inflammatory types based on an integrated genomic signature, which is likely to improve current classifications and will pave the way for more tailored treatments.

The buzz-word of the conference was ‘super-enhancer’. An enhancer is a DNA motif upstream of a gene that when bound by a transcription factor protein stimulates the reading of that gene. The over-activation of oncogenes such as MYC in some other pediatric cancers has very recently been shown to be due to chromosomal rearrangements leading to multiple enhancers accumulating upstream of these oncogenes (Pfister, Heidelberg). There is active research now into whether MYCN and other oncogenes in neuroblastoma are super-enhanced in this way. Bromodomain inhibitors such as JQ1 are the leading candidates for targeting super-enhancers.

Above we have seen how immunotherapy and various other promising treatments can have strong effects, but ultimately the cancer will return. To understand why this is the case, we need to know how the nature of tumours changes during treatment and at relapse. This is beginning to be answered now, and it is high time. Whereas, say, 4 years ago clinicians would say there was no justification for the invasive resampling of tumours after treatment, the mood has now changed. Derek Oldridge and John Maris (Philadelphia) investigated

(Continued on page 6)
samples at diagnosis compared to relapse and found, surprisingly, that there was in some cases very little overlap in the mutation signature, suggesting that the tumour clones that caused relapse were either new or an undetectably small subset of the original disease. Detailed sampling of different disease sites and of all the clones within tumours is clearly needed to unravel what is going on.

Various UK groups, most of whom The Neuroblastoma Society have awarded grants to in the recent past, gave a good account of themselves giving talks or presenting posters, including the groups of Sue Burchill (Leeds), Lou Chesler (Sutton), Rob Mairs (Glasgow), Anna Philpott (Cambridge), Arturo Sala (Brunel), Violaine Sée (Liverpool) and Deb Tweddle (Newcastle). Our long-standing surgical Medical Trustee, Keith Holmes (St. Georges), gave a typically suave talk reporting the positive correlation between successful tumour excision and survival in SIOPEN patients.

What was missing? Japanese groups were represented in various interesting posters but were given very few talks. Radiotherapies were as usual also relegated mostly to posters, despite the new generation showing great promise in early trials and being included in Phase III trials for ultra-high risk patients. I think this is because they are thought of as therapies that are too blunt to be interesting, whereas in fact they target tumour cells through interesting and unique cell surface receptors that offer great treatment specificity, plus there is great interest in how radiosensitisers work and how radiotherapies synergise with other treatments.

Attendance at ANR meetings is now dependent on membership, with subscriptions payable by researchers. So ANR has become an established world-wide neuroblastoma organisation, through which much could be delivered. However, there is a clear danger that the organisation could become too conservative, focusing on already successful groups and themes to the exclusion of the more speculative research that will lead to future generations of treatments.

The Neuroblastoma Consortium, a world-wide umbrella group of neuroblastoma charities that would sit nicely alongside the ANR, was introduced for the first time at this meeting. Our Chair Susan Hay has stepped up to be Chair also of the Consortium and will host a full day of meetings for charity representatives at the next ANR in 2016 in Cairns, Australia.

Guy Blanchard, Research Trustee
SPRING CONFERENCE & AGM

On Saturday, 26 April, Members, Trustees and Researchers gathered together for the Society’s Spring Conference and Annual General Meeting in London. Two of our funded researchers were invited to talk about their work: Dr Andrew Stoker (UCL, London) described his work on oxovanadium compounds, and their effects on neuroblastoma differentiation and senescence; and Dr Robert Falconer (University of Bradford) explained his work developing inhibitors of polysialyltransferases as a new approach to neuroblastoma treatment.

Alex Bremer gave a moving account of his daughter Lizzy’s illness and the family’s determination to help other neuroblastoma families by raising awareness and funds for research. His wife, Miriam, had taken on a string of sporting challenges and other family members and friends organised a variety of events raising a huge amount for the Society.

Following her daughter’s diagnosis of neuroblastoma, Vicky Vidler along with her sister Emma Ambrose decided to be positive and entered a half marathon to raise funds for research. Vicky and Emma explained that an idea that started out with four-six people escalated into a small army of over 200 running in support of Lily.

The formal business of our AGM was swiftly concluded with our Treasurer outlining the accounts and commenting that fundraising revenue was significantly higher than this time last year boding well for our forthcoming grant round.

Finally, the morning concluded with the Annual Draw ably run, once again, by Tori Oldridge. First prize of an iPad Mini went to Mr & Mrs James McGuire, a box at Ascot Racecourse was won by Warren Elliott and the week’s holiday in Cornwall went to John Bruce-Ball.

Thanks to the Thomas Ball Children’s Cancer Fund, Bounce PR, Mark Stone, Shore Hatton and Steve Smith for their contributions to the Annual Draw; to Michelle and Trevor Langford for sponsoring lunch; and to Alistair Hay and Rock Townsend for allowing use of their premises.
CAMPAIGNING IN EUROPE FOR CHILDHOOD CANCER

The International Confederation of Childhood Cancer Parent Organisations held its European meeting in Valencia in May, returning to the city where it was founded 20 years ago. Around 100 delegates from some 29 countries and all the world’s continents attended, mainly parents and staff associated with national charities and foundations, but with a significant number of teenage survivors of cancer.

The Spanish health minister and the provincial health minister attended a reception to mark this anniversary before the work of the conference got under way. This high level representation anticipated a number of reports indicating that ICCCPO and its associates are having some success in influencing health policy, including advising the World Health Organisation’s cancer team on childhood cancer.

Much of the conference involved reports and discussions about Europe-wide initiatives, many of them with a significant emphasis on seeking to ensure that children all over Europe have access to the best treatment and care. A key example is the European Network for Cancer Research in Children and Adolescents (ENCCA) which is running a series of projects covering all aspects, from causes of cancer, through new treatments and access to care, to quality of survivorship. The programme is led by SIOP Europe (the co-ordinator is Ruth Ladenstein who is a leading neuroblastoma specialist). Examples of activities include a survey of how well different countries are implementing the SIOPE standards of care, influencing the adoption of the new regulations for clinical trials (agreed in April) and the revision of regulations for paediatric medicine. An ultimate aim is the creation of a ‘European Virtual Institute’ for clinical and translational research.

Several presentations dealt with survivorship, with initiatives including:

- Guidelines for long term follow-up to ease the transition from childhood surveillance to adult follow up (PanCareSurFup).
• Seeking to ensure that survivors have same quality of life and opportunities as peers, focusing on post-treatment complications and effects (PanCareLIFE).

• ‘Survivorship Passport’, allowing medical and other details of treatment and implications to be accessed by the patient and any health professional via a web-based portal.

Other presentations dealt with national activities, including a French project to assess the costs of travel and accommodation for families during treatment. From the UK, Chris Copland spoke about his role as a patient/parent representative with the National Cancer Research Institute (NCRI) in assessing and approving clinical trials (many of which are now concerned with neuroblastoma). Danielle Horton Taylor discussed her work helping to improve communications about clinical trials to make the accessible and understandable for parents and patients, through a group known as PORT (Paediatric Oncology Reference Team).

In workshops and discussions the consensus emerged that the priorities for ICCCPO Europe should be care for teenagers and young adults, and long-term follow-up. While these are not areas of major focus for the Neuroblastoma Society in terms of our research funding, we are of course interested in them and in particular we hope our work will mean that there will be more patients to follow up in the long term. As ever with such gatherings, it was great to feel the positivity and energy of parents and – especially – the patients themselves, and to see the many ways in which they are working to improve childhood cancer care. I hope that we will be able to continue to hear about and contribute to this work via our membership of the Childhood Cancer Parents Alliance.

Finally: there is no getting away from jargon and acronyms at these meetings and that was recognised in a discussion about whether ICCCPO should consider a change of name and branding. ICCCPO is a bit of a clunky acronym (not to mention that many people speak it as ‘icky-poo’ which doesn’t have the nicest ring for an English speaker!) and the full name is even more unwieldy. On the other hand it is well-recognised and people are quite attached to it. Much of the discussion was familiar from our own debates which led to our very successful rebranding including the relaunched website, and of course in the UK NACCPO changed to CCPA fairly recently. In the end the consensus was for change, so having got to know the organisation for the first time I will now have to learn a new name …

*Steve Smith, Trustee, Health Community & Family Liaison*
Raphaella

In January 2012 my life became complete. Following ten years of IVF and many unsuccessful attempts we had just had our second and third children, twins Raphaella and Caeden who, along with their older brother Caius, made us a very happy family of five. We felt we had finally left behind the difficult years and could get on with our lives. Then unfortunately on the 14th of April the same year our world came crashing down. Our beautiful, desperately wanted little girl was diagnosed with neuroblastoma. We spent the next five months between intensive care, high dependency and the ward and despite having a joy and desire for life Raphi gained her angel wings on September the 8th. I returned to work the following January—I am a secondary school teacher at a local comprehensive school, Magdalen College School, Brackley, where I was met with great support from colleagues and pupils. So when selecting the House charity of the year the students voted wholeheartedly in favour of The Neuroblastoma Society. They raised just over £1200 by selling hot drinks, decorating mugs and a non-uniform day. Many pupils, staff and parents gave very generous donations. On the House awards evening, Tracey Davies from the Society very generously gave up her time to accept the cheque on the Society's behalf and gave a wonderful speech on the work of the charity and why it's so important to support research into neuroblastoma. Overall I would like to thank Magdalen College School for their generous donation, Tracey for giving up her time so selflessly and the Society and all its supporters for their tireless work into searching for a cure for this horrible disease so others won't gain their angel wings.

Philippa Moggridge
Man Oh Man!

Earlier this year, Winchester House of Holy Trinity School, Crawley, Surrey, organised a fundraiser to benefit the Society. This took the form of a Man Oh Man competition, in which members of staff and the school council were judged on their abilities to carry out a number of manly (and not so manly) tasks. There was plenty of fancy dress involved, and nobody taking it too seriously. The serious part though was that it raised £483 for the Society. Ben Sharp, the trustee who looks after corporate and community fundraising, attended a cheque presentation at the school, and awarded a certificate of thanks to Winchester House, in May. In keeping with the theme, the cheque presentation happened on another fancy dress day, and the Sainsbury's employee who is presenting the cheque to Ben is in fact Micah Cox, head of Winchester House.

Fundraising for Lent

We’re really grateful to the pupils at St Thomas Aquinas Catholic School, Kings Norton for raising over £800 for the Society. The students, from Newman House, organised collections and other fundraising activities during the Spring term, leading up to the Easter break.

The pupils selected The Neuroblastoma Society to receive all the funds they had raised after hearing that the niece of one of their teaching staff died of the illness. Sue Davies from the Society attended an assembly at school on 3 June to collect the cheque. She said “It was very generous of the pupils of Newman House to choose to support The Neuroblastoma Society, and they have done so well to raise such a large amount during just a few weeks. This money raised will all go into new research projects which The Neuroblastoma Society is funding, starting in September this year”.

Sky Diving for Hannah

In March, Paul Burchell took on the challenge of jumping out of a plane to raise funds for neuroblastoma research in memory of his daughter Hannah. It’s an awful long way down but Paul enjoyed the experience and has made over £3k for the Society—thank you Paul!
Ruby Wedding

Mr and Mrs Balmer from Lanarkshire have recently celebrated their Ruby Wedding Anniversary and organised a fundraiser in memory of their son, Niall, who was six years old when he died in 1987. Ishbel tells us:

“Along with close family and friends, a ladies night was arranged, complete with a group to help us dance the evening away and chip butties for the interval! We had raffles, a tombola and bingo, with all the prizes donated either by local business people, or those at the event. The generosity shown was absolutely overwhelming and we raised an amazing £2,500! Although we had money donations before the event, the vast majority of the final total was the result of the money the ladies spent on the night. Around 85 of us were there and it was a wonderful, if somewhat emotional, evening.”

Thank you!

The Friendship Ball

My name's Denise and as a paediatric nurse I was aware of neuroblastoma and what it was, but truly ignorant to what a diagnosis of this really meant. That was until January 2013, when my niece Rosie was diagnosed with neuroblastoma stage 4. It's scary and the scary doesn't stop when the treatment is complete - every time the check up scans come, we wait with baited breath and a head full of prayers awaiting results!

Thankfully for us Rosie is doing really well and we hope and pray she continues to do so!

As a family we felt it important to raise awareness and some funds for future research, so that every family faced with this diagnosis has the best possible chance of a cure!

On May the 3rd we held The Friendship Ball, named so because nobody gets through cancer without the support of good family and friends and I'm delighted to say we raised £2,000 for The Neuroblastoma Society!!

Denise Power
Rock On!
Thank you to David Davies from Rhuddlan in North Wales, for donating a hand-made rocking horse to the Society and raising £500 towards the Society's research fund.

Teddy Tombola
Fighting Neuroblastoma held another Teddy Bear Tombola at the Gateshead Metro–Centre raising £150 for neuroblastoma research. Many thanks!

David vs Goliath!
A massive £800 raised at the Tae Kwon Do fight night organised by Chris Reeve at the Watton Sports Centre, Norfolk! Fantastic achievement all round - our thanks to everyone!

BADA Charity Gala
The 2014 British Antique Dealers’ Association Charity Gala was held on the opening night of the BADA Fair, Wednesday 19 March and this year was in aid of The Neuroblastoma Society. 250 guests were invited from 6pm to enjoy champagne and canapés prepared by first class event caterers, showgirls, unique auction and terrific raffle items whilst viewing the wonderful art and antiques for sale within the Fair. The event was held in memory of Lizzy B who lost her courageous battle with neuroblastoma in July 2013, just two days after her second birthday. It was a fabulous evening and raised much needed funds for research. Our thanks to BADA, the Lizzy Bremer Legacy and all involved.
Lily’s Legends

On 23 March, over 200 runners took part in the Brentwood Half Marathon, raising funds for neuroblastoma research in support of Lily.

Here’s a selection of sea of gold! Thank you, everyone!
**Watford 10K**

It was a privilege to run and raise money for the Neuroblastoma Society. It was a challenge, but I did it! I now know that an undulating course is code for hilly! With the incredible generosity of friends and family I have managed to raise £400 for the charity. I ran in memory of Lily Gray who sadly lost her battle with neuroblastoma last year. She was a beautiful and brave little girl and I hope that one day with funding and research a cure can be found for this nasty disease.

*Heather Hankinson*

**BUPA London 10K**

Geraldine Jones (left) and Eleanor Mahmoud (right) certainly deserved their medals after completing the BUPA London 10k in May. Geraldine was running in memory of Lizzy Bremer and Eleanor in memory of her brother Neil and both have raised a considerable sum for neuroblastoma research.

Thank you for your support!

**Edinburgh Half**

After a wonderful success with his 500 for Alex fundraising venture last year, Chris Noble is still running! Dodging the showers, he completed the Edinburgh Half Marathon at the end of May. Well done, Chris and many thanks!

Entries for the 2015 Edinburgh Marathon Festival are now open—distances range from 1.5k junior races to a full marathon. Why not get a team together and run for neuroblastoma research!
Trustee Power

136 miles seems like an odd sort of distance, but trustee Ben Sharp covered this distance by firstly running the Milton Keynes Marathon, and then 4 weeks later cycling a 110-mile sportive in the Chiltern Hills. Both distances were covered in good weather and Ben completed both events. No speed records were broken or world records set, although he did get 6 punctures on the cycle ride which set a new course record. Ben's fundraising for these two linked events has so far raised £2500, in memory of his son Alex, and as importantly allowed him to model the Society's new cycling top. Some people will do anything for a new piece of kit.

London to Paris

In April, Michelle Jones put on her cycle jersey and, accompanied by Floppy Bunny, set off on a gruelling trip to Paris to raise funds for neuroblastoma research. Cousin Molly had been treated for the disease as a baby and is now 12 years old. One of over 150 cyclists, the trip was hard work but Michelle said the atmosphere was fantastic. We think Michelle is also fantastic for taking on this challenge and for raising such a wonderful sum.
Canal Walk

On 17 May 42 ladies and gentlemen took on the challenge of walking around 10 miles from the Falkirk Wheel to Linlithgow along the Union Canal, to raise funds for neuroblastoma research and to help young Ashlee Easton and her family have a special holiday in Disneyland.

Ashlee’s granddad, Brian O’Connor, organised the event: “Just let you know the charity walk on Saturday was a great success. Most of us did the walk in 3hr 30mins. One of the girls who struggled with a leg problem right from the start did it in 5hrs which was a great achievement for her and I’m so proud of all who took part.”

Oliver’s Kicking Cancer!

Huge thanks to Team Marchant who are raising funds for neuroblastoma research and for Keech Hospice. This is Oliver’s story:

“At the age of 1, Oliver was diagnosed with Horner’s Syndrome (droopy eyelid and small pupil) in his left eye. It is a harmless condition but it’s vital to discover the cause. After a year of scans and further investigations Oliver received a diagnosis of Neuroblastoma in May 2013 and was classed as intermediate risk. The aggressive treatment schedule included six rounds of chemotherapy, an operation to remove the tumour, radiotherapy and 6 cycles of an oral chemotherapy drug. Oliver has been so resilient throughout his gruelling treatment and we have been so proud of how our little son has been kicking cancers butt!”

The first of two fundraising events this year took place on 8 June when Team Marchant ran the St Alban’s Half Marathon raising a fantastic sum for their two charities.
**Down Among the Pines**

On Monday the 15th April myself and four friends (Megan Sanders, Joshua Ryan, Elliot Broad and Catherine Mitchell) set out from home in a car loaded with people and bikes to do a sponsored cycle ride around Bedgebury Pinetum to raise money for the Neuroblastoma Society, a charity close to my heart as my sister died of neuroblastoma 16 years ago. It would have been her 18th birthday on April the 19th. Luckily for us it was a beautiful sunny day so wearing the yellow t-shirts proudly we set off. With the promise of a picnic to look forward to at lunch we cycled nearly 16km, all off-road. After lunch most of us continued on to do a further 13km before calling it a day having cycled 29km. The car was much quieter on the way home! When we had finally got all of the sponsorship together we found we had raised a terrific £853.95 between us all. I am extremely proud of my friends and thankful to everyone who sponsored and supported us.

*Jennifer Trevarthen, aged 16*

**Ashbourne Tri**

Les Harrison from Derbyshire sent the Society offline donations received in support of his daughter, Megan, who competed in the Ashbourne Triathlon in aid of the Society. Les tells us: "Megan had neuroblastoma as a ten week old and, at the time, had paralysis in both legs. Subsequent treatment on ward E39 of Queens Medical Centre, Nottingham, has seen her make a full recovery as can be witnessed by her magnificent achievement of completing the event in under two hours."

Well done, Megan, and Thank you!
Golf Day at Princes Golf Club, Sandwich, Kent
Friday, 5 September 2014

Once again, Princes Golf Club will be hosting a Golf Day in aid of The Neuroblastoma Society. Masterminded by Nick Bushell, the day’s events will include breakfast rolls, coffee, dinner and entertainment, plus of course a round of golf at the prestigious, championship Links golf club. Teams of four are invited to enter at a cost of £600 per team.

As well as a round of competitive golf, the day concludes at dinner with not only a silent auction but a live (and lively!) auction too. And to provide the entertainment, comedian Paul Boardman—son of Stan—will be on hand to keep everyone laughing!

So don’t miss out—reserve the date in your diaries and watch this space and our website for information on how to enter.

2-3 August 2014
The London Triathlon
Don’t miss out!
BE PART OF IT
Email sports@neuroblastoma.org.uk
To sign up NOW!
CLIC Sargent, the UK’s leading cancer charity for children and young people, has launched an innovative new guidance pack designed to help teachers support children with cancer.

The *Cancer and school life* resource contains advice and a lesson plan which can be used by teachers in a school where a pupil has been diagnosed with cancer. The pack also includes a DVD featuring children who have had cancer and their school friends speaking about their experiences.

For more information visit www.clicsargent.org.uk.

**Volunteering**

Would you be interested in volunteering for the Society? As a charity run entirely by voluntary effort, we always welcome offers of help with every aspect of running the charity. Wherever you may be in the country, however much time you may have available, you will be helping us to fund more neuroblastoma research. We rely on our volunteers to make a difference for children with neuroblastoma so please get in touch today—we’d love to hear from you. volunteers@neuroblastoma.org.uk

**OUR HELPERS**

**Annual Draw**
Mrs Tori Oldridge—annualdraw@neuroblastoma.org.uk

**Collecting Boxes**
Mrs Sue Davies—collectingboxes@neuroblastoma.org.uk

**Donations**
Mrs Wanda Davies, Accounting Officer, 49 St Asaph Road, Dyserth, Rhyl, Denbighshire, LL18 6HG—donations@neuroblastoma.org.uk

**Newsletter Packers**
Mrs Maureen Stevenson & Mr Frank Townley

**Parents’ Booklet**
Mrs Eileen Rowe—parentsbooklet@neuroblastoma.org.uk

**Pin Badges**
Mrs Mary Waterhouse—pinbadges@neuroblastoma.org.uk

**Sports Events**
Mrs Sue Davies—sports@neuroblastoma.org.uk

**Stamp Appeal**
Mrs M Wade, 13 Longacre Road, Cressing, Braintree, Essex, CM77 8HG

**Website Coordination**
Mrs Tori Oldridge—media@neuroblastoma.org.uk
It is with great sadness that we report the news that Cyril Wade has passed away. Cyril and his wife Marie have co-ordinated the Society’s Stamp Appeal since their grandson, Sam, died of neuroblastoma aged 3 in 1993. For over 20 years Cyril and Marie have received, sorted, trimmed and sold the stamps raising much needed funds for the Society. Many of you will have received a thank you letter from Cyril and I’m sure will wish to join us in sending our condolences to Marie, Graeme and all the family—Cyril will be much missed.

We were heartened, however, to learn that Marie is intending to continue the Stamp Appeal. Thank you, Marie.

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!

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

Lorica Employee Benefits from Hampshire, the sum raised on their Annual Golf Day in September 2013.

‘ZORB’ football team, Lower Sixth Form at Ysgol Glan Clwyd, St Asaph, money raised as part of Welsh Baccalaureate fundraising for charities.

Miss Louise Sutherland from Glasgow, in memory of her nephew's little boy, Grant Sutherland.

Mr & Mrs Phillips from London, to celebrate the 80th Birthday of Mr Maurice Bennett.

Mr & Mrs Wimbush from Manchester, in memory of their great granddaughter, Casie Heyes.

Donations given in memory of Mr Renton Pyle, as requested by his son, Mr Graham Pyle from Bromley.

Mr Jeremy Jacobs at Organics Recycling Group from London, proceeds from Gala Dinner on 20th March.

Mr Kevin Murphy from London, in memory of his beloved grandson, Michael O'Donnell, and Michael’s beloved Nanny, Eileen.

Mrs Emma Lack from London, to support the Society’s Work.

Mr & Mrs Worsley from Kent, in memory of their dear friend, Jackie Blackwell.
Mrs Maureen Stevenson from Surrey, money collected from the residents of Heathside Court, Tadworth, in memory of her grandson, Ben Stevenson.

Ms Justine Laymond from Essex, off line donation given in support of her running the Brentwood Half Marathon.

Mr & Mrs Philip and Linda Cooper from Spalding, money raised at their snack bar over the last year.

South Essex College, proceeds from a “dress down” day at the college.

Mrs Cherry Blanchard, proceeds from Christmas carol singing – donation from The Napp Educational Foundation, Cambridge.

Sara Staker from Reading, and a donation from Sara’s friend in lieu of payment for some baby items. Sara’s grandson, Daniel, was diagnosed when he was eight months old and will celebrate his 11th Birthday this year. Daniel is a very keen gymnast and enjoys many other sports.

IPC Network Services from London, in support of Carly Crawley running the Brentwood Half Marathon.

Mrs I Warner from Welling, in memory of Christopher James Wright.

Mr A Wright from Croydon, in memory of Christopher James Wright.

Mr & Mrs Rowe from Lymm, a donation from their friend, Steve Kennedy, in memory of their granddaughter, Lily Gray.

Mr John Sutton from Worcestershire, in memory of Mr J. Davies.

Ms Emma Hussey from Rayleigh, her employer’s contribution in support of Emma’s running the Brentwood Half Marathon.

Chris and Lindsey Yearsley from Stoke-on-Trent, offline donations in support of their latest fundraising event in memory of their daughter, Jasmine Sophia Yearsley.

Jamie Stewart from London, a donation from his employer, Reed Business Information, in support of Jamie’s running the South Devon Marathon in February. Jamie run on behalf of friends of his family whose two-year-old daughter, Sienna Riley, is battling neuroblastoma.

Mrs A J E Huckstep from Kent, in support of Justine Laymond running the Brentwood Half Marathon.

Mr Chris Noble, a donation received in support of his fundraising in aid of the Society.

The Caleta Hotel, Gibraltar, proceeds from a fundraising event in aid of the Society.

Mr & Mrs G L Wright from Chatham, in memory of their son, Christopher James Wright.

Mr Chris Ewell from Sittingbourne, content of a collection box at Miller’s Bar.

Mrs Irene Graves, a donation from Ladies Meeting Point in Chester Le Street, Co. Durham to support the Society’s work.

Sumner Pridham from Royal Tunbridge Wells, in support of Julie Farragher running a half marathon in aid of the Society.

Sound and Vision Express from Cheltenham, proceeds from the recent fundraising event at Cheltenham Civil Service Club.

Mr Phil Reeves from Bath, content of a collection box.
Mrs Maureen Stevenson from Tadworth, money raised by the residents of Heathside Court by holding a Craft Stall in memory of Maureen's grandson, Ben Stevenson.

Mrs June Drennan from Glasgow, in memory of her grandson, Grant Sutherland, who would have been 20 on 23rd March 2014.

Mrs Shelagh Ashley from Bedford, a donation from Reg Kensall who held a one-man exhibition to celebrate his 100th Birthday and raised a wonderful amount for a charity.

Mrs Maureen Stevenson from Tadworth, further donation from the residents of Heathside Court in memory Ben Stevenson. Special thanks to Mrs Pauline Ellis for her donation.

IFF Research Ltd from London, to support the Society's work.

Dr Simon Cooke from Norwich, further proceeds from the Austrian Challenge in May 2013.

Jennifer O'Brien from Glasgow, sponsorship money received in support of her Swim with Sharks on 28th July 2013.

Mr Dennis Jeans from Norwich, to support the Society's work.

Mr Jeremy Jacobs from London, further proceeds from ORG conference.

Mr Michael Horton from Wallasey, half of the proceeds from “Pub Dare” for his brother to shave off his mustache.

Elaine Reeves at Usborne Publishing for the work of the Society.

Emma Ambrose from Raleigh, sponsorship money for the Brentwood Half Marathon and a donation from Jean Bentley.

IFF Research Ltd from London, to support the Society's work.

Ken Stimpson Community School from Peterborough, to support the Society's work.

Mrs Tamara Stewart-Wilson from St Andrews, donations received in memory of her son, Dougal Stewart-Wilson, and including proceeds from Big Chess Competition at the Caleta Hotel in Gibraltar.

Magdalen College School from Brackley, proceeds from a fundraising event, Mufti Day.

Mr Alexander Clarke from London, offline sponsorship for running the London Marathon.

Mrs Maureen Stevenson from Tadworth, a donation from Mrs Pauline Ellis in memory of her friend, Mrs Pat Sheehy, and in memory of Maureen's grandson, Ben Stevenson.

Chris Denman and Simon McCrea from West Lothian, sponsorship for Leg Shaving at Images in aid of the Society.

Chris Ewell from Sittingbourne, proceeds from the sale of mixed metals to APM metals to support the Society's work.

Further donation from Ken Stimpson Community School from Peterborough, to support the Society's work.

Mrs Ann Greenfield, in memory of Tom Willson, to mark the twelfth anniversary of his sad loss.