

Advances in Neuroblastoma Research, Toronto, June 2012

This is the biennial meeting at which a large proportion of the world's neuroblastoma researchers convene to talk about their work. Organised by Sylvain Baruchel, the meeting was huge, with over 500 delegates from 32 countries presenting over 100 talks and 300 posters. I will concentrate in this short report on my impression of the major changes in two years since the previous meeting in Stockholm.

The analogy of horses (gene mutations) driving carts (tumour growth) was used by Plenary speaker Tak Mak, Toronto's pre-eminent oncologist, to differentiate between therapies that target specific tumour cell mutations (horses) and treatments that target growth of tumours in general (cart). The former leads to personalised medicine, with treatment geared to the specific errors that drive



each patient's tumour. Such geared treatments would hopefully involve few side effects, though many different treatments and diagnostic tests would be required. The alternative is to target the cart (tumour growth) with systemic treatments, such as is currently done with conventional chemotherapy (with severe side-effects) and more recently with immunotherapy. Tak Mak's contention, though he was talking about cancer in general, is that we have largely failed to find effective treatments for specific oncogenes and their pathways that are altered in cancers, and that we should turn our attention to developing more effective systemic treatments. In particular, he was excited by the potential to control tumour energetic demands, the potential for immunotherapy, and the potential to exert control over the

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Editor's Note

We begin this issue with a round up of the Advances in Neuroblastoma Research conference earlier this year and look to see what progress has been made and what is hoped for in the future.

We list the projects funded by the Society in their latest funding round and give more detail on two of them.

The second in our series on clinical trials looks at some of the reasons why there are so few neuroblastoma drug trials funded by pharmaceutical companies.

And we have many of your wonderful fundraising stories to tell and photos to show. We send our thanks to everyone who has raised funds for the Society—your support really will help us to make a difference.

As demand for the Society's funding grows, so we need to expand to enable us to meet that demand. On page 11 we are making a request for people to volunteer to help with the organisation of the Society. We would love to hear from you!

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

Articles for the Winter Newsletter
DEADLINE 30 November

erroneous number of gene copies that occur in most cancers.

So is it true that for neuroblastoma we have largely failed to find agents that successfully target particular genes or pathways, and what progress is being made with systemic treatments?

1 Targeting specific gene mutations

One of the major changes in the last two years has been the completion of the sequencing of many tumour genomes (and also epigenomes and transcriptomes) and comparing these to host patient genomes. This was expected to reveal many new mutations that drive neuroblastoma tumour formation - so-called somatic mutations. John Maris (Philadelphia) reviewed sequencing results, showing that, unlike in adult cancers, few mutations have repeatedly arisen in neuroblastoma tumours. The most common is in the gene ALK, present in 14% of high risk tumours, and in terms of treatment progress ALK has been a success story. Phase I & II trials have been completed in the US for the anti-ALK drug Crizotinib, which has shown response in some (but not all) types of ALK-mutated tumours (Mosse, Philadelphia). ALK-screening of all tumours will soon become routine, selecting patients for Crizotinib treatment. Note that the time it has taken from the discovery of the role of ALK in neuroblastoma in 2008 to finding response in a Phase II trial is less than four years, which is pretty remarkable.

Of the other neuroblastoma-predisposing mutations, the most promising seemed to be in the genes LIM01 and Lin28B. The list is a little longer but of increasingly rarely mutated genes. A consequence of the mutation of many of these genes is that, indirectly, MYCN is over-expressed, and a MYCN-Lin28B-Let-7 micro-RNA axis has been converged upon by different groups as being key to the cause of neuroblastoma in many children (Diskin, Philadelphia & Molenaar, Amsterdam). This insight must surely simplify the search for treatments for a significant proportion of high risk disease. Also, the gene ATRX, which is involved in how DNA is packaged in the cell nucleus, has been found mutated predominantly in older children who have particularly poor prognoses and its discovery is a breakthrough in understanding, if not yet treating, non-MYCN amplified 11q-disease (Cheung, MSK).

Further evidence that somatic gene mutations are not as important as previously thought in directly causing neuroblastoma come from the various computer-based gene classifiers that are being developed to predict disease outcome, so that treatment can be tailored appropriately to the patient. Andre Oberthur (Cologne) and others have found that gene classifiers on their own are not very successful, and only become so when multiple classifiers are combined with other non-genetic factors such as patient age.

So why do neuroblastoma tumours arise with surprisingly few new gene mutations? There are various possibilities. First, children may inherit various mild genetic predispositions that if tipped, either by chance events or by a new mutation or by an environmental effect, could lead to neuroblastoma. Second, we know that gene copy number is often awry due to chromosomal rearrangements/aberrations, which leads to different quantities of gene-products being produced rather than none as often occurs with gene mutation. Third, new epigenetic modifications (tags on DNA) could be important. Fourth, maybe the immune system fails to do its job for non-genetic reasons. Finally, maybe neuroblastoma should be considered a metabolic disease, in which the rates of tumour cell energy production and consumption are controlled by a large and complex network of genes, none of which are vital. Treatment approaches to much of this list would entail what Tak Mak called targeting the cart rather than the horses.

2 Systemic treatments

There was huge interest in immunotherapy at this meeting, and compared to other areas there seemed a flowering of pragmatic anti-GD2 treatment variations and promising new treatments such as a vaccine and CAR T-Cell immunotherapy, that will enter trial over the next few years both in Europe (Lode, Greifswald and Anderson, UCL) and the US (Sondel, Wisconsin and Yu, San Diego).

Encouragingly, long-term follow up from Alice Yu's trial that first proved the benefit of immunotherapy (anti-GD2 + IL-2 + GM-CSF) shows that 7 year event (relapse)-free survival is around 50% for the immunotherapy arm compared to 30%, still an improvement of 20%.

There were many presentations from Memorial Sloan-Kettering groups (Cheung & Kushner) that I found very difficult to assess. Their results are incredible - both in the sense of amazing but also in the literal sense of unbelievable. It is never quite clear what the biases were in who was enrolled in treatment and they do not do randomised controlled trials in the way that COG and SIOPEN do. I was pretty convinced though that the MSK anti-3f8 immunotherapy should be trialled by COG or SIOPEN, since it seems to be effective for the 11q-disease typically found in older children, who desperately need a life-line.

Treatments targeting tumour metabolism and gene copy number per se are in their infancy in neuroblastoma, though there is real interest in these. Overall I would call it a score-draw between personalised medicine and systemic approaches, and a pragmatic research portfolio should include aspects of both. The other important story that has been around for a while but for which more evidence has accrued in the last two years is that for many high risk tumours, unless slowly-dividing

New research funded by the Neuroblastoma Society

'tumour-initiating cells' are targeted as well as the bulk of rapidly dividing cells, relapse is likely (Shohet, Texas and Schliermacher, Paris). This remains a challenge for both approaches.

Charities

Many international charity representatives were also present and there was much discussion, particularly about the potential for charity collaboration over co-funding international trials and pooling information on what research each charity is funding. Sue Cohn (Chicago) has been successfully driving the formation of an interactive database (iINRGdb) which gives researchers access to an unprecedented combination of (anonymous) patient, tissue bio-bank and genomic profiling information. Europe lags behind, particularly in the pooling of tissue bio-banking information and the charities could help drive this. I hope that at the Cologne ANR meeting in 2014 there will be more formal discussions between many interested charities. In the meantime, this potential will be explored further by the William Forbeck Foundation who will bang charity heads together.

Abstracts of all Toronto talks and posters are available at

http://anr2012.com/uploads/ANR2012_Programme_Web_06_18_12.pdf.

Dr Guy Blanchard, Research Trustee

As reported in the last newsletter, the Neuroblastoma Society has awarded funds to six research projects and two clinical trials (see box on page 8).

We aim to provide you with details on two of these awards in each newsletter over the next 18 months. In this issue, we describe the approaches and work planned by Dr Louis Chesler and Dr Marie Boyd.

Research to evaluate new ALK inhibitory drugs and treatment strategies



A new research project entitled "Development of ALK-targeted therapeutic strategies using genetically engineered models of ALK-driven

neuroblastoma" will be directed by Dr Louis Chesler at the Institute of Cancer Research laboratories based at the Royal Marsden Hospital in Surrey. Dr Chesler and his team are particularly interested in how the two genes, MYCN and ALK, contribute to the aggressiveness of neuroblastomas and how to evaluate new drugs that target these genes. With support from the Neuroblastoma Society, Dr Chesler and his American collaborators have already developed preclinical systems which mimic the formation of very high risk human neuroblastomas. The

models provide a test system to evaluate the effectiveness of new drugs and provide information which is taken into account when designing clinical trials.

The new research is based on the reasonable premise that inhibition of ALK will be effective as a treatment against neuroblastomas with ALK abnormalities. Using preclinical models associated with genetic alterations in MYCN and ALK, Dr Chesler and co-workers have shown how resistance to crizotinib, the first ALK targeted drug to be used in clinical trials, might be overcome by simultaneously targeting MYCN. This work was published in the journal *Cancer Cell* in July 2012.

Dr Chesler will use preclinical models with alterations in both MYCN and ALK to evaluate new drugs that target ALK, either alone or in combination. He has negotiated access to potentially promising drugs from several laboratories in the UK and America. During the 3 years of this project the following studies will be carried out:

- a series of currently available drugs that inhibit ALK, including an antibody against ALK, will be tested in the preclinical models for their ability to overcome the resistance to crizotinib
- preclinical models covering other ALK abnormalities seen in neuroblastoma patients will be

evaluated and characterised

- ALK targeted drugs currently under development in other laboratories using modern high throughput screening systems will be tested in the original and new preclinical models to establish their potential effectiveness for treating human neuroblastomas.

The results of these studies will accelerate the introduction of new ALK-targeted drugs for neuroblastoma into the clinic and provide information to design future clinical trials for high risk patients. Dr Chesler has described his work on the development and characterisation of the preclinical models to the Society at the 2010 Annual General Meetings and we look forward to hearing more about this important work in the future.

Research to improve radiotherapy treatment



Dr Marie Boyd,
Reader in
Translational
Biology, Strathclyde
Institute of
Pharmacy and
Biomedical Sciences

A new research project entitled "Improving the effectiveness of radiotherapy for neuroblastoma by targeting hypoxia" will be directed by Dr Marie Boyd at the University of Strathclyde. Radiotherapy uses high energy rays or particles to kill cancer

cells and can be delivered in two ways. External beam radiotherapy is from a radioactive source external to the body and is usually targeted at a specific site, for example a primary tumour. The second form of radiotherapy used for neuroblastoma patients is by injection of radioactive MIBG into the blood stream to deliver radioactivity to tumour sites throughout the body. Unfortunately some tumour cells have low levels of oxygen, a state known as hypoxia, which makes them more resistant to both forms of radiotherapy (and chemotherapy). These hypoxic cells may survive after treatment and eventually cause the patient to relapse. Hypoxia has also been associated with an increase in the aggressiveness of tumours. Dr Boyd and her team are trying to make radiotherapy more effective by identifying drugs which inhibit the molecules associated with hypoxia-induced radioresistance. Some of the molecules that induce this radioresistance in cells are known and inhibitors of these molecules are available.

The premise of this study is that if the mechanisms used to prevent cell death in hypoxia can be inhibited, both external beam and MIBG radiotherapy will be more effective. This 2 year study will

- Establish levels of molecules associated with hypoxia, including HIF-1 and DNA repair factors, in cell-based systems grown in

conditions of high and low oxygen and test the effect of a range of inhibitors of these molecules

- Establish the effect of external beam and MIBG in cell-based systems in conditions of high and low oxygen and test the effect of radiation in combination with molecules identified in the first part of the study which could sensitise cells in hypoxia

As a result of these studies in cell-based systems, molecules might be identified which increase the effect of radiotherapy particularly in hypoxic cells (a known resistant sub-population). The potential for these molecules to act as suitable drugs in preclinical and clinical settings will then need to be investigated.

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Recently Funded Research

University of Strathclyde

£118,158 over 2 years was awarded to Dr Marie Boyd, Dr Anthony McCluskey, Professor Andrew Pearson and Dr Mark Gaze for a project entitled "Improving the effectiveness of radiotherapy for neuroblastoma by targeting hypoxia". This work will begin on 1st January 2013.

Institute of Cancer Research

£213,844 over 3 years awarded to Dr Louis Chesler for a project entitled "Development of ALK-targeted therapeutic strategies using genetically engineered models of ALK-driven neuroblastoma"

This work will begin on 1st October 2012.

University of Bradford

£105,863 over 2 years was awarded to Dr Robert Falconer, Dr Steven Shnyder, Professor Laurence Patterson, Dr Catherine Cullinane and Dr Jens Stahlschmidt for a project entitled "Development of inhibitors of polysialyltransferases PST and STX: a novel strategy for the treatment of neuroblastoma"

This work will begin on 15th October 2012.

University of Liverpool

£51,702 over 1 year was awarded to Dr Diana Moss, Dr Violaine Sée, Professor Paul Losty, Professor Barry Pizer and Ms Dhanya

Mullassery for a project entitled "Exploitation of embryonic microenvironments to unravel new mechanisms to down regulate MYCN in neuroblastoma cells".

This work will begin on 1st October 2012.

University of Cambridge

£110,494 over 2 years was awarded to Dr Anna Philpott for project entitled "Manipulating Ascl1-mediated proliferation versus differentiation in Neuroblastoma: Towards better differentiation therapy". This work will begin on 1st October 2012.

Institute for Child Health

£129,356 over 2 years was awarded to Dr Andrew Stoker and Dr Stephen Hart for a project entitled "Identification of tyrosine phosphatases that suppress differentiation and promote survival in neuroblastoma cells". This work will begin on 1st October 2012.

Clinical trials and studies

£30,000 was awarded to SIOPEN (International Society of Paediatric Oncology - Europe Neuroblastoma) through the UK co-ordinator Dr Kate Wheeler to provide "Financial support for half of the UK's SIOPEN annual levy for the next three years 2012-2014".

£11,876 was awarded to Dr Michael Pike, Dr Ming Lim and Dr Bethan Lang to support the "UK Multicentre Study of Children with Opsoclonus Myoclonus Syndrome (UMSCOM)"

Pharmaceutical companies and neuroblastoma clinical trials

Although neuroblastoma is responsible for 15% of paediatric cancer deaths, UK and European pharmaceutical companies (pharma) have almost no involvement in neuroblastoma clinical trials. This may be due to the exacting drug-trial regulations and to the modest financial rewards from producing drugs for paediatric oncology, given the limited number of patients compared with the major adult cancers. It may also reflect a lack of productive collaboration between pharma and the research community. Here we take a look at the problems and suggest some solutions.

Pharma are encouraged by the European Medicines Agency (EMA, the clinical trial regulatory authority) to trial new drugs on paediatric patients through Paediatric Investigation Plans (PIPs). Each time an application to trial a new agent for an adult cancer is submitted (by pharma or indeed by academia), it must be accompanied by a PIP. The PIP is a plan for how the new treatment will also be trialed on paediatric patients in a Phase I setting to establish dose limits, and how this would progress to a Phase II trial and beyond, all being well.

Since 2007, more than 1000 PIP applications have been submitted. Encouragingly, more than 500 of these have been approved, 41 of them in

paediatric oncology. But none of these have been for neuroblastoma. If there is no equivalent disease in children to the adult disease against which the drug is being trialed, pharma can obtain a 'waiver' or official exemption for a PIP submission. Neuroblastoma is not the equivalent of any adult disease. This situation seems rather extraordinary since it is often the case that the same gene and/or biochemical pathway that is being targeted in an adult cancer trial is known to be awry in neuroblastoma, plus there may be strong pre-clinical evidence to support using the drug against neuroblastoma. For example, the anti-ALK drug Crizotinib that has recently been shown to be effective in a Phase II neuroblastoma trial in the US, was given a PIP waiver and not trialed in Europe because Crizotinib was originally developed for adult lung cancer, for which there is no equivalent childhood disease. Moreover, even when a PIP has been submitted, the timing of the start of the proposed Phase I trial can be subject to a 'deferral', awaiting proof of safety and efficacy in adult patients.

A separate consideration is that single drugs only rarely have large anti-neuroblastoma effects whilst multiple agents can often act synergistically to great effect. EU Legislation requires an understanding of the safety and efficacy of the single agent before its

use in combination, so progress to combination treatments will be slow under the current regime. A further complexity for Europe is that each trial has to be reviewed and approved by each participating country's regulatory authority, which can be time-consuming and complicated.



Left: Professor Gilles Vassal—Institut Gustave-Roussy
Right: Professor Andy Pearson—Royal Marsden

Gilles Vassal (Institut Gustave-Roussy) and Andy Pearson (Royal Marsden), representing European paediatric oncology clinicians, have been proactively campaigning on behalf of neuroblastoma patients. They want the European trials regulations to change and would like to see pharma involved in neuroblastoma clinical trials. Phase I trials can be done within single countries, but Phase II & III trials will need international collaboration, for example through SIOPEX & COG (the organisations of European and US clinicians respectively) so as to give access to a sufficient number of patients to make these trials run on a viable time scale. Pharma need to be involved at all of these levels, but particularly in Phase I trials of new compounds.

So what can be done?

The EMA is aware of the failure of the current regulatory system for neuroblastoma, but finding the

appropriate amendment(s) is proving to be difficult. One possibility may be to adopt elements of the American approach, where both carrot and

stick are used. Over there, the equivalent of a PIP is rewarded by additional exclusivity for the drug.

Vassal and Pearson have been highlighting the need for academic researchers and neuroblastoma clinicians to find ways to collaborate with pharma more productively. They have identified three priority areas. First, a common strategy needs to be developed about which promising compounds should be prioritised in trials, in the full context of possible treatments. Second, creative trial design is needed to maximise the number of agents that can be trialed for a given number of enrolled patients. Third, for each trial that is run it is vital that as much can be learnt as possible, even (or particularly) if a promising compound fails to show an anti-neuroblastoma effect. This means monitoring the progress of drug activity against disease in detail with biomarkers. For example, disease load can now be assessed quantitatively through the amount of tumour mRNA circulating in the blood, as pioneered by Sue Burchill (Leeds). For immunotherapy,

Hands Up!

As a national charity run solely by unpaid volunteers, we are always keen to hear from those who would like to help us in our aim of funding more research into this aggressive disease. We are proud to say that currently about 95% of all donations to the Society go directly towards neuroblastoma research—a remarkable achievement—and one that we would like to continue. If you would like to join us, we would be delighted to hear from you. Currently, we particularly would appreciate help



with our website and with corporate fundraising, but we would welcome your help in many different capacities. It doesn't matter where you are based in the country—what matters is that you want to help make a difference to the lives of children with neuroblastoma both now and in the future. Your time, energy and enthusiasm would be worth a great deal to the Society. Learn more by contacting Natalie at volunteers@neuroblastoma.org.uk

increasingly sophisticated pharmacodynamic measures that reveal details of the complex patient immune response are being used.

Parents and charities can also play a vital role in continuing to highlight the need for neuroblastoma trials and ensuring that health officials and pharma give the disease the attention that it is due.

And the drugs companies themselves? Clearly they need to be financially viable if they are to continue the work they do. And great strides are being made in finding life-saving drugs for many illnesses. Although there are only a relatively small number of cases each year, neuroblastoma is a highly aggressive and very difficult-to-treat cancer and therefore presents a particular challenge. What could be more satisfying for a company than to say – we made real progress in tackling this disease?

Dr Guy Blanchard, Research Trustee

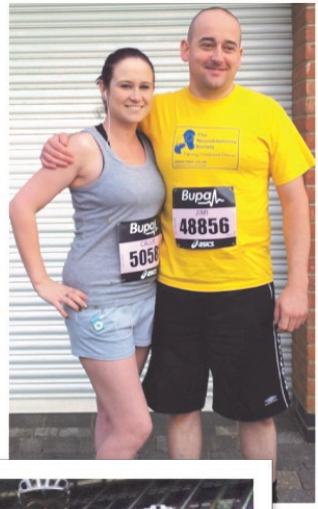
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A Yellow Array of Fantastic Fundraisers:
Clockwise from top left: Great British Ride team; Callie & Jimi—GNR; Beverley & Grant—Pedal for Scotland; John Hunt Event skydive team; Channel Challenge—Team Zak; John Hunt Event - Ironman Challenge.
THANK YOU ALL!

Fundraising Stories

Team Zak v The Channel

Three fitness fanatics braved the perishing waters of the English Channel to swim the twenty three mile distance between Dover Harbour and the rocks of Cap Gris Nez, in memory of Zak Hobbs, who sadly became another victim of neuroblastoma in September 2011.

Simon Harris, Matt Harris and Nick Hague are the three brave swimmers who faced the tough challenge of the swim. All three have completed half Iron Man and triathlon competitions in the past, and in 2010 Simon and Matt cycled from John O'Groats to Lands End for the Neuroblastoma Society.

The Channel Swim is one of the toughest challenges the three have faced to date, and was Simon's idea.

"We wanted to do something in memory of Zak after his brave two year battle with neuroblastoma, and having already done the cycle fundraiser, the swim was next on the list," explains Simon. "Both Matt and I were keen to do something extreme to encourage people to support the Neuroblastoma Society after Zak died last year, and we roped Nick in too."

Simon is a Director of New Store Europe, and they have generously paid for the boat and pilot for the challenge, to ensure that the Neuroblastoma Society and Helen &

Douglas House Hospice, receive all the monies raised.

Nick Hague started out at 12am on 8 September from Shakespeare Beach, Dover. The conditions were really rough and choppy so progress was slow to start. Apart from the extreme cold of the night the swimmers struggled with terrible sea sickness when in the small boat and weren't able to eat or drink anything until the sea calmed a little at first light. Once the sun came up the swimmers started to increase pace. Matt took the final leg and all three swimmers swam the last half mile to Cape Gris Nez reaching it at 1.45pm - a total of 13.45 hours and covering 24 miles. They will have raised just under £10k for the Neuroblastoma Society and Helen & Douglas House Hospice .

*A fabulous achievement—thank you!
Donations can still be accepted at:
<http://uk.virginmoneygiving.com/team/TeamZak>*



John Hunt's Olympic Childhood Cancer Event 2nd—5th August 2012

The Hunt family and friends held their own Olympic Event to raise funds in memory of John Hunt who should have been celebrating his 21st birthday, but sadly lost his own challenge against neuroblastoma, at the age of 5. The Event was planned based on a Team Ironman Challenge, being a bespoke cross country, road and hills Marathon of 26.22 miles, Swim 3 Miles, 112 miles Cycling along the Olympic route, plus skydive by John's sister Zoe (who overcame her fear to jump), with partner Joe.

Our target was to raise £5000, but this amount has been exceeded and still growing. The family wish to thank and congratulate all the participants and sponsors for their wonderful efforts.

As word spread, more friends wanted to join us with their own contributions. The John Hunt Event (as we named it) extended with an additional Tri-event on Hayling Island, being a 21 miles walk, 2.1 miles swim and 21 miles cycle. Well done to Adrian, who completed her challenge in 8 hours and 17 minutes. Elaine, Rob and Veronica joined us to complete a 10 Km team walk.

Janet has forfeited her morning coffee treat on the way to work this year and donated the money that she saved.

The weather was mostly kind to our participants, but cyclist Chris fought his way through torrential rain during the hardest part of his ride, that being three times up and down Box Hill in Surrey. He also rode 120 miles in just eight hours, instead of the planned 112, leaving him a bit sore, thanks to missing a turning. The bespoke 26.22 mile Marathon run by Dad Keith, was a gruelling run with a mixture of road, cross country and added hills to make



The active Event Team:
Front row: Zoe, Caroline, Adrian and Elaine
Back row: Keith, Chris, Peter, Joe and Rob

it more interesting, unfortunately having to dodge oncoming trucks during the downpour. Despite enduring a knee injury, he managed to complete in a creditable time of 4 hours 50 minutes. Peter, our swimmer, proved himself a true Olympian, taking just 1 hour and 48 minutes to complete 200 lengths of the

pool, counted and cheered along with his family.

Of course, thanks must go to marshals, organisers and supporters who came to Maidstone and en route to cheer the competitors along. Thanks go to David Lloyd Leisure Centre for use of their pool and

Barclays Bank who have agreed to match one of the walkers £ for £ on her individual sponsorship, also to the Vines BMW Group for allowing Chris to static cycle in the showrooms.

Raffles and other events have all helped towards this worthy cause. Caroline (Mum) has abstained from birthdays and Christmas this year by not giving or receiving presents and cards, but donating instead to the charity what would have been spent.

This was an amazing weekend and it was a wonderful event bringing friends and family together to collectively raise funds for a deserving cause. Also, to mark what should have been a special occasion in the short life of a brave and memorable young boy.

<http://www.justgiving.com/Keith-Caroline-Hunt-In-Memory-of-John-Hunt>



Pedal for Scotland

Our thanks to Beverley and Grant McIntyre for taking part in this gruelling event. 47 miles from Glasgow to Edinburgh—3hrs 50mins—£700 and rising—brilliant achievement! Thank you!

A Song for Lily-Mae

If you are visiting Ireland about now, you may well hear Elton John's beautiful song *Tiny Dancer* being sung or hummed or listened to rather more than you might expect. Thanks to Stephen Macken, a professional television cameraman and an amateur musical theatre performer with Galway Musical Society, a choir of almost 300 voices is coming together to record *Tiny Dancer* as a single to raise funds to help a little girl, Lily-Mae, who was diagnosed with Stage IV neuroblastoma earlier this year, and to fund neuroblastoma research. The aim is to make as much noise about neuroblastoma as possible by hitting the Irish Christmas Number One slot. We are grateful to mum and dad, Judith Sibley and Leighton Morrison, for donating half the proceeds from sales of the song to the Society. So do please buy the song from iTunes when it is released.

And if you have any family, friends, acquaintances, or contacts in companies and businesses in Ireland, ask them to download the song, too, to help it reach Number One in the Irish Charts this Christmas.



Packing Power

With the young son of a friend currently going through treatment for neuroblastoma, the Society was an obvious choice when considering which charities to support. As part of a long term fundraising plan, which culminates in a self-funded trek through Jordan in November 2013, I had contacted several local supermarkets for a bag packing opportunity. We were offered a slot on Saturday 4th August in Tesco, Rutherglen in Glasgow. I also decided I would organise a tombola to run instore on the same day, sending out feelers to friends and family for donations, unwanted gifts etc. These same friends and family provided the team of packers and I was able to make a rota to cover the 6 hour shift on Saturday afternoon, with some working for an hour or two and others there for the whole day, splitting their time between packing and manning the tombola.

Some of the public happily gave donations before we had even set up. Others would come to chat, to tell their own stories or relay other people's experience of the illness. It's something I have seen before, those who are or have been affected by cancers or other illnesses, reach out, want to share their stories and give all they can to support you. Taking the



time to talk to these people is just as important as packing their bags or selling them raffle tickets.

The packing itself is hard work but was also great fun. At the supermarkets request, we try to leave every other checkout without a packer, to give shoppers the choice. Also, we connect with the till operators and

ensure each shopper is willing to have their bags packed by us.

The tombola was a great success, 4 tickets for £1 with loads of prize-winners. We had a box of lollipops for the younger kids who stopped by, very popular!

Before our pasta and wine, we counted the contents of the buckets, tombola takings etc, we had raised over £1150, this being split between 2 charities, The Neuroblastoma Society benefitting by £576, adding to myDonate page totals. This money continues to grow and will be boosted by upcoming plans for a craft fair in December and a Race night/raffle sometime in early 2013. I will continue to add other events etc leading up to the Jordan walk late in 2013.

From my side, all I can do is support my friend and raise awareness through these events and raise as much money as I can for the continuing work and support the Society provides. Lastly, thanks to all my friends who gave up their time and tombola donations to make this day worthwhile.

Margaret McLaughlan

Sports Events

It's been a high profile year for sport. Something called the Olympics must have inspired even more people to take part in sponsored events. Many thanks to all of you out there.

There is still time to register with us for the Great South Run, 10 miles in the glorious sun of Portsmouth on a route that passes the historic Dockyards and HMS Victory with the final yards on the seafront. What a great finish!

By the time you read this our runners will hopefully have fully recovered from their efforts in the Great North Run and we'd like to say thank you very much for all your hard work and we hope to hear some of your running stories.

Next year we are delighted to have places in the Brighton Marathon taking place 14th April 2013 so if you would like to get on the waiting list contact us as soon as possible. I'm sure you'll agree this will be a fine location for those 26 miles and 385 yards or if you prefer 42.195 kilometres!

If you want 10k we have places in the two London races: Bupa and the British London –get in touch.

We have lots of you doing your own sporting thing and don't forget we are happy to supply t-shirts or running vests and a fundraising pack with sponsor forms. Justgiving.com is an excellent way to collect sponsorship

without having to chase people around the pub.

Contact us at
sports@neuroblastoma.org.uk

Great British Ride—LEJOG

The beginning: We're cycling from Land's End (Cornwall) to John O'Groats (Scotland) – from the most South-Westerly point on the UK mainland to the most North-Easterly point. This is a distance of just under 900 miles, and we are planning to do it in just nine days from 15th September to 23rd September 2012 .

And the end: So, we obviously did it, and there is a huge sense of relief this morning at not having to fill water bottles, put on smelly kit and damp shoes, 'lube up', and saddle up for another day of hard graft. But also of course a lingering disbelief at what we have achieved and how far we have come.

Seven men, five bikes, one bus, nine hundred miles, nine days and one special little boy. Plus a huge amount of generous donations. Thank you all!
<http://greatbritishride.wordpress.com/>



Christmas is Coming!



Give as you Live helps you raise money for your favourite charity at no cost to you, every time you shop online.

This is because thousands of stores have signed up to donate a percentage of every purchase you make online when they discover Give as you Live.

It takes seconds to download Give as you Live and then when you shop at your favourite online stores, they will donate part of every purchase you make, without you putting your hand further into your pocket.

www.giveasyoulive.com/Christmas

Christmas Party!

On Sunday, 9th December, *Fighting Neuroblastoma* will be holding a Christmas party at The Coachmans, Whickham - 4-6pm. Adults are free, children £5 to include a visit with Santa and a gift. Any donations for raffle prizes would be most welcome.

Contact:

fightingneuroblastoma@hotmail.co.uk

Society Christmas Cards

Our Christmas cards are available now. We have four new designs to choose from: *Christmas Stag*, *Twinkle Little Star*, *Poinsettia* and *Present* and *Through the Door*. Order forms are enclosed with this newsletter, can be downloaded from our website, or



contact publicity@neuroblastoma.org.uk to be sent a copy.

Sending our Christmas cards means not only that you are helping to raise funds for neuroblastoma research, but also that you are spreading information about this devastating disease so that others may be encouraged to join us. Thank you for your support!

Letter from Santa

Would your child like to receive a letter from santa?

If so please send us a self addressed pre-paid envelope. Please enclose details of your childs name & age.

Also include a cheque or postal order [No cash] for a minimum of £2.95 made payable to The Neuroblastoma Society

Please post to...
Team Valley Printers, 321H Mayoral Way,
Team Valley Trading Est, Gateshead, NE11 0RT

Please note that all requests must be received by December 12th



Polar Express Bell

For only £5.95*

£1.00 from each bell sold will be donated to The Neuroblastoma Society for fighting children's cancer.



*please add £1.50 for postage & packing

To order your polar express bell contact Sam McDine at Whickham Cottage Crafts email: whickhamcottagecrafts@gmail.com Tel: 0791 937 4650

Winter Ball

Help Fight Childhood Cancer

Friday 23rd November
at the Lancastrian Suite
(Near to the Metrocentre)

7pm – 12.30am

Reception drinks & 3 course meal
Auction • Raffle



Entertainment from UK crooner of the year

Jason Isaacs

and soul singer **Sam Dickinson**
Compere and magician **Steve Keys**



Tickets: £35

Dress code: fabulous!

For tickets contact the Fundraising Committee
at fightingneuroblastoma@hotmail.co.uk or
call Louise on **0775 287 8492**
Call Justine on **0759 575 5951**



Annual Charities Christmas Fayre

Our thanks to Margaret Sutherland and her wonderful friends who will once again be selling Society Christmas cards at the Annual Charities Christmas Fayre in the Glasgow City Chambers Banqueting Hall on Wednesday, 14th November.



Teddy Bear and Sweetie Tombola

Fighting Neuroblastoma will be holding a Teddy Bear and Sweetie Tombola at Gateshead Metrocentre on Sunday, 2 December to raise funds for neuroblastoma research. They would love to see you on the day! If you have any new

teddies, soft toys or sweeties to donate to this event, or are able to help out, please contact Louise or Justine on fightingneuroblastoma@hotmail.co.uk

Donations

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

Mr & Mrs Pugh from Watford, to support the Society's work

Terrence Bell from Romford, in memory of his son-in-law's dearly loved Nan, Doll Holt, who died recently aged 94.

Mrs Sue Smith, Stagecoach Group Office Manager, in memory of Mrs Elizabeth Chapter who recently passed away, to support the Society's work as requested by her son.

Last Cawthra Feather Solicitors from Bradford, proceeds from a dress down day.

Mrs Maureen Maher from Dunstable, proceeds from a sale of her handmade greeting cards in memory of Haley Spokes.

Co-Operative Group, Booster Fund, matched the amount raised by *Mr & Mrs Yearsley* from Stoke-on-Trent at the curry evening in memory of their daughter Jasmine.

St Mary's Church, Amersham, a special display of flowers was arranged for the Jubilee weekend and a collection was held for the Neuroblastoma Society.

Mrs Julie Lynch from Crawley, held a charity evening at home, prepared food for her six good friends and sent the evening's proceeds in memory of her beloved grandson Ben Stevenson who died five years ago at the age of 3½.

Ben Sharp from Buckinghamshire, offline donations in support of "Spinning for Alex" fundraising event. The Spinathon was held on 28th April.

Mrs L Williams from Croydon, a donation towards the Society's general funds. Her grandson, treated for neuroblastoma in his childhood, is now 32 years old.

Sara Thornett from West Sussex, to support the Society's work.

G.F. Raby from Luton near Peterborough, to support the Society's work.

Mrs Daphne Roth from London, marvellous amount from various fundraising events.

Mr Stuart Wilde from *The Robinson Lodge of Instruction* from Kent, money raised at the Lodge's Sunday Luck by a Raffle and a donation from the Lodge's President.

Mr & Mrs Chadney from Abingdon, further donations in memory of their son Luke Solomon Chadney.

Mr Wayne Mark Webber and Miss Jessica Ann Roke from Tiverton, donations in memory of their beloved son Rhys Samuel Webber who passed away on 6th April 2012, aged 2 years.

Justine Kilin from Newcastle upon Tyne, who with other fundraisers did a presentation on neuroblastoma at her local Rotary Club and received a donation to support the Society's work. Justine also sold many of our pin badges.

Mr H. Raby Jnr from Cambridgeshire, to support the Society's work.

Mr & Mrs Worsley from Sevenoaks, in memory of Mr Albert Styman.

Xylem in the UK, accepted nomination of the Society by one of their employees from *Water Process Ltd in Hoddesdon* and awarded a donation to help fund the Society's research into neuroblastoma.

Great Wilderness Challenge from Scotland, to support the Society's work.

T P O'Reilly & Mrs A J O'Reilly, to support the Society's work.

A kind donation from Relief Chest Scheme, The Freemasons' Grand Charity, made at the request of the *John Lord Lumley Lodge, L5885*.

Dean Porter, money raised by his daughter *Liena* who ran 5 miles in a Fun Run in Felixtowe.

Ian Henderson from Suffolk and *C Fitzpatrick*, off-line sponsorship money for Holly Fitzpatrick skydiving. Thank you to everyone who supported Holly!

Mrs J Cole, in memory of her son Josh Kadan.

Mr Alan Fenn, in aid of *Xelabus* fundraising efforts in memory of Alex Blair. For every

model bus sold, *Xelabus* donates £5 to the Society.

Cadmore End CoE Combine School from High Wycombe, to support the Society's work.

Durham High School for Girls, proceeds from a cake stall organised by Year 8.

APM Metals from Sittingbourne, proceeds from scrap metal collected by *Chris Ewell*. Thank you to all at *The Keresley Arms* for their recycling.

Lingfield Primary School from Surrey, money raised by Year 6 School Council children.

Mr & Mrs Taylor from Gt. Dunmow, to support the Society's work.

Monkseaton & District Pool League, accepted *Mr Stephen Cockrell's* nomination of the Society and sent the raffles and an annual competition proceeds to support our work.

Mrs Mary Gough from Watford, in memory of her husband Cyril who has died recently – money kindly donated by Cyril's family and friends.

Miss Rachel Roberts from St Helens, took part in a parachute jump in memory of her cousin Ruby Lindup and raised a great amount for the Society.

Miss Lindsey Hyde from London, towards the Society's general funds.

WAP McColville Ltd, from Presteigne in Powys, a marvellous donation to support the Society's work.

Cecilia McKelvey from London, in memory of her daughter Zara McKelvey who died in 1992 – money raised at End of Term Tea Party at the University of Greenwich.

Mr & Mrs Burchell from West Sussex, in memory of their dear Granddaughter Hannah Louise Burchell who would have been six years old on 19th July.

Ann Hughes from South Ruislip, a donation to the Society in lieu of wedding presents for Bill and Jan Sharp.

Mr & Mrs G. D. Martin, in support of the Society and Alex Sharp and his family.

Ben Sharp sent many kind donations made up of the following: donations in lieu of birthday

presents for Ben's neighbour Julian Rhodes' 40th birthday; donations in lieu of wedding presents for Ben's father Bill Sharp's recent wedding to Jan; money left over in the account following street's Diamond Jubilee Lane Party at their village; a donation from Rickmansworth Rotary Club following a talk given to them by Ben.

Mrs June Grant from Northampton, donations made by the family in memory of Josephine Boeg-Clarke who passed away on 2nd June. Josie lost her grandson to neuroblastoma when he was 18 months old.

Mr W. J. Hutchins from Norwich, a donation on behalf of the Hutchins family in celebration of the wedding of Bill and Jan Sharp.

David and Caroline Bayes from Buckinghamshire, to celebrate the marriage of Bill and Jan Sharp.

Mrs Lisbeth Shepherd from Orpington, in loving memory of her nephew Oliver Langford.

Windlesham House School from West Sussex, money raised by *Mhairi McLay* with a little help from her mother, Helen, as part of her "Spirit of Windlesham" award. Thank you to everyone for their generous donations.

Donation sent by *Holy Trinity and St Wulstan, Heworth*, collection made at the funeral service for Mr Fred Wilson, as requested by his family.

Mr & Mrs Yearsley from Stoke-on-Trent, sent the Society donations received in memory of their daughter Jasmine. They continue to raise money for the Society through Jasmine's JustGiving page.

Mrs Sajida Abbas from S. Coldfield, sent a donation to support the Society's work.

Kevin Hanlon from Surrey, run the Edinburgh Marathon and obtained from his employer, *Hewlett Packard*, a donation for the Society under their Charity Match scheme.

Stephen Broadbent from Huddesfield, sent many donations requested in lieu of presents for his 60th Birthday. Stephen's daughter, Lucy, was diagnosed with neuroblastoma when she was 3 years old. She is now 32 years old, and celebrated her first wedding anniversary recently.

James & Anne McGuire from Middlesex, asked for donations to the Society in lieu of flowers at the funeral of their daughter Sophie McGuire. Sophie was diagnosed with Stage IV NB in April 2009 and sadly died on 5th August 2012. They continue to support the Society through Sophie's JustGiving page.

Andrew Knowles from Norwich, run a cake stall at the end of the school year at Notre Dame High School in Norwich in memory of his brother William, who lost his battle with neuroblastoma at the age of 11, and to raise awareness of the disease.

Donations in Loving Memory of Matthew Dale from: Matthew's Parents, Sisters & baby Brother (*Gary, Lucy, Rachel, Daisy & Harry Dale*), and from Matthew's neighbours: *Sarah, Andrew & William Goldstone*.

Darren and Julie Thompson from Cumbria, donations received in memory of Declan Thompson and proceeds from a coffee morning and quiz sheets – all organised by Julie and her mum-in-law, *Audrey Thompson*.

The *Coronation Lodge* No 2898 Benevolent Fund, in memory of John Hunt. The donation was requested by John's Grandfather and Uncle who are members of the lodge.

Robinson Lodge of Instruction, proceeds from a raffle held on 5th August in memory of John Hunt.

Boughton Monchelsea Scout Group, organised a Tour De France event in memory of John Hunt and sent proceeds from John Hunt Event to the Society.

Miss Veronica Hill from Kent, money raised through her 10 km sponsored walk in memory of John Hunt.

Caroline and Keith Hunt from Kent, sent many offline donations in memory of their dear son John Hunt who would have been celebrating his 21st Birthday on 6th August.

Please send donations to:

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

Cheques payable to:

The Neuroblastoma Society

Thank you!

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 over 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 or by phone on 01904 633744, for an informal chat.

OUR HELPERS

Annual Draw	Mrs Tori Oldridge— annualdraw@neuroblastoma.org.uk
Befriending	Mrs Caroline Nicolaides— befriending@neuroblastoma.org.uk
Collecting Boxes	Mr Laurie Bradshaw, The Chimes, 7 Hall Farm Court, Worsendale Road, Bishop Wilton, York, YO42 1ST collectingboxes@neuroblastoma.org.uk
Donations	Mrs Wanda Davies, Accounting Officer, 49 St Asaph Road, Dyserth, Rhyl, Denbighshire, LL18 6HG donations@neuroblastoma.org.uk
Monthly Draw Club	Mrs Michelle Stephenson, 9 Reservoir Road, Erdington, Birmingham, B23 6DA
Newsletter Packers	Mr & Mrs Maureen Stevenson & Mr Frank Townley
Parents' Booklet	Mrs Eileen Rowe—please contact via the Secretary
Pin Badges	Mrs Mary Waterhouse— t.waterhouse@live.co.uk
Stamp Appeal	Mr & Mrs C Wade, 13 Longacre Road, Cressing, Braintree, Essex, CM77 8HG
Website Co-ordination	Mrs Tori Oldridge— media@neuroblastoma.org.uk

SOCIETY HELP LINE
FOR INFORMATION AND GENERAL ENQUIRIES

020 8940 4353



www.neuroblastoma.org.uk

