

# **NEUROBLASTOMA NEWS**

The Neuroblastoma Society Quarterly Journal

Issue 60 — Summer 2010

# Society funds four new research projects

The Society's biennial research grant round has just concluded with the award of funding of almost  $\pounds_{525}$ ,ooo for four research projects at university laboratories across the UK, the second largest set of awards in the Society's history.

# Almost £525,000 awarded in research grants

Steve Smith, Society Chairman says, "It is very satisfying to be able to put the funds raised by

our members and supporters to such good use, and I must record again my appreciation to you all for your efforts – and encourage you to continue fundraising so that we can sustain the increasing level of research into the causes and treatments of neuroblastoma".

The projects cover understanding how neuroblastoma originates, the effects of oxygen on NB cells, making models to identify treatments for correcting faulty genes and using a purer form of MIBG.

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The Society announces the inaugural Neuroblastoma Research Symposium on Friday, 3 December 2010 in Cambridge. Leading experts in the field of neuroblastoma research will be speaking at the Symposium which will bring together researchers, clinicians and

# Neuroblastoma Research Symposium

charities involved in neuroblastoma research. This is an exciting new venture for the Society which

we hope will encourage researchers into the field of neuroblastoma.

Our Research Trustee, Guy Blanchard, attended the Advances in Neuroblastoma Research Conference in Stockholm in June. This Conference attracts specialists in neuroblastoma research from around the globe to present and discuss their work. Guy's report highlights the most upto-date thinking and ideas from the neuroblastoma research community.

For a selection of your fundraising stories and all the news from your sporting activities, turn to pages 10-15.

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9th Annual Golf Day 2010

Organised by Georgie's Fund Supporting The Neuroblastoma Society Tuesday, 28 September West Byfleet Golf Club, Surrey 18 holes of golf followed by prizegiving dinner For more information and to enter a team, see: www.georgies-fund.com

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# **Editor's Note**

Welcome to the Summer Edition of Neuroblastoma News. After four years at the helm, we bid farewell to Sue Davies, with many thanks for her patience and perseverance in producing the Newsletter each quarter. Thank you Sue. We are also saying goodbye and thank you to Tracey Davies who is stepping down as Trustee responsible for fundraising.

As you will already have noticed, we have a new format for the newsletter. We hope you like it and would welcome your views. Many thanks to Jenny Humphreys for her help in the redesign.

There is much to consider in this newsletter. In particular our four new research projects are explained; we have an interesting write up of the Advances in Neuroblastoma Research Conference; and we announce our inaugural Neuroblastoma Research Symposium.

In addition, there is a selection of the many stories of your fundraising achievements. Due to your efforts there are more events than we have space to feature but we thank everyone who has raised funds for the Society—without you none of our work could happen.

#### Shirley Clark

Have you been fundraising for The Neuroblastoma Society? Would you like to share your story? Please send contributions and photos to the Editor at: **publicity@neuroblastoma.org.uk** or by post to:

54 Forest Road, Richmond, TW9 3BZ

Articles for the Autumn Newsletter

••••••DEADLINE 31 AUGUST••••••

# Society funds four new research projects

Successful applicants and their projects:

#### • Dr Louis Chesler, Institute of Cancer Research

Modelling ALK over-expression in neuroblastoma, and the therapeutic efficacy of novel ALK inhibitors (£150,000 over 3 years). This project will develop tumour models incorporating mutations of the ALK gene and examine its effects on its own and with the MYCN gene. It is based on the principle that cure rates could be improved if treatments can be devised which correct the action of the faulty genes that are associated with neuroblastoma.

#### • Professor Rob Mairs, Cancer Research UK Beatson Laboratories, Glasgow

Exploitation of bystander effects to maximise the efficacy of no-carrieradded [1311]MIBG used in combination with cytotoxic drugs for the treatment of neuroblastoma (£200,622 over 3 years). This project will examine the effectiveness of a purer form of MIBG which carries a radioactive label on every molecule, in tumour killing, including how to use it in combination with other drugs such as topotecan and PJ34. It is planned that clinical studies will then be designed based on the findings.

#### • Dr Deborah Tweddle, Northern Institute for Cancer Research, Newcastle

Differentiation of human embryonic stem cells to sympathetic neurones: understanding the pathogenesis of neuroblastoma ( $\pounds$ 60,785 for 1 year). This project will work towards understanding how neuroblastoma originates in early human development, by establishing a model system for normal development of the sympathetic nervous system using human embryonic stem cells, then encouraging them to develop so that differences in normal neural cells and neuroblastoma can be investigated.

#### • Dr Violaine See, University of Liverpool

Determining the role of oxygen microenvironment in the reprogramming and aggressiveness of neuroblastoma cells (£112,651 over 2 years). This project is investigating how levels of oxygen in neuroblastoma affect tumour aggressiveness and spread, including measuring the effect of different drug treatments on neuroblastoma cells in both normal and low oxygen levels.

12 applications were initially received, with two being withdrawn when the applicants secured funding from other sources. The remaining proposals were reviewed by independent referees, whose reports, along with the proposals themselves, were considered by the Society's Scientific Advisory Board (SAB) at its April meeting. The SAB's recommendations were considered and approved by the Trustees at the May Board meeting and applicants informed of the outcomes. The successful applicants will initiate their projects in the next few months, subject to acceptance of the Society's T&Cs and in one case of some minor revisions to the planned work. I am, as always, very grateful to the members of the SAB: Chairman Dr Chris Mitchell and Professors Steve Clifford, Paul Losty, Andy Pearson and David Walker, Thanks to Professor Adrian Thrasher and Sue Ballard for arranging for the meeting to be held at the Institute of Child Health. The awards process was organised and run entirely by Yvonne Boyd and Guy Blanchard, whose great efforts made the process run smoothly. **Steve Smith** 

# Spring Conference & AGM

#### Steve Smith, Chairman

The Society held its 2010 Spring Conference and Annual General Meeting on Saturday 24 April at St Winefride's Church Hall in Kew. Approximately 40 members and supporters of the Society attended to hear reports on some of the research supported by the Society, and to receive updates and reports on other aspects of our activities from Trustees.

Guy Blanchard, Research Trustee, gave an overview of the key areas for research into neuroblastoma, from understanding the basic biology of cell development in the foetus through to the development of effective and targeted therapies. This was a highly illuminating presentation, and it was especially helpful to see where the research that we have funded is situated on the overall map, and hence to see the areas where our funding is helping to understand the cause and explore treatments for neuroblastoma. We were especially grateful to Guy given that he had only arrived back in the UK 24 hours or so previously, having been forced to spend several days stranded in Nova Scotia due to the airspace closures!

Dr Louis Chesler, a current grantholder, then spoke about the work that he and his colleagues are engaged in at the Institute of Cancer Research, which is focused mainly on drug discovery and development, initially in pre-clinical situations before seeking to transfer into the clinic. As well as improving our understanding of the potential therapies, he explained the challenges that he and other researchers face in getting interest and support from pharmaceutical companies that see limited commercial opportunities in childhood cancer, compared to other areas - underlining the significance of our support for research.



Dr Louis Chesler & Prof Susan Burchill

One very encouraging aspect of his talk was the degree of communication and collaboration with other research groups in the UK and beyond, including the US and Japan. This was also a key point of Professor Sue Burchill's presentation, where she explained how her team in Leeds is able to use work carried out in the rest of Europe within their work on highrisk neuroblastoma. She has been engaged in this sort of work since the early gos, and her current project is the second to receive funding from the Society.

Our final speaker was Dolly Jones, who was due to run the London Marathon the next day for the second year in a row in her quest to raise £26,000 in memory of her father (a keen runner) and her cousin Locke who died of neuroblastoma aged 18 months. She talked about her motivation and her experience both of last year's event (which she ran despite an ankle injury which left her on crutches for a while afterwards) and of seeking sponsors. It was a moving and inspiring talk and we were very grateful to her for coming. The following day she ran a 4 hour race, a magnificent effort, and comfortably exceeded her fundraising target too.

In the formal AGM, the Chairman spoke briefly about the year's activities, and in

particular reiterated the thanks of all members and supporters to the three Trustees standing down since last year's meeting – Dennis Bignell, Dr Peppy Brock, and Sue Davies (see the Annual Report for more detail). He welcomed formally those Trustees who joined up during the year, Guy Blanchard and Yvonne Boyd, and in particular thanked them for their work in organising the 2010 grant round, enabling the Scientific Advisory Board to meet the following week (28 April) to consider the applications. One additional person had come forward as a potential Trustee, and he invited others to consider doing the same - there is always plenty to do!

James Duberly, Hon.Treasurer, spoke to his report on the financial position of the Society and on developments so far in 2010. Although fundraising had shown some signs of slipping in the early part of the year, a substantial legacy and other contributions had combined to provide a sum in the order of £550,000 for grant



Left: Dolly Jones (centre) Below: Dr Chesler, Des Fordham, Steve Smith and Prof Burchill drawing the raffle





Receiving a cheque from Lynne Christian on behalf of Georgie's Fund

awards when the Trustees meet to consider the SAB's recommendations. He identified the main trends in expenditure (which remains, remarkably, at less than 5% of income) and income, with the decline in interest rates in particular having a significant impact. He concluded with the traditional encouragement that we all get out and carry on raising money!

Des Fordham oversaw the annual draw, with winning tickets drawn by Louis and Sue (and including, to general amusement, a ticket bearing the name of one Dennis Bignell!) – winners will be notified in due course if they haven't already heard. The Chairman was presented with cheques from Georgie's Fund and from Chris Ewell's recycling efforts before the meeting concluded with a buffet lunch and informal discussions.

It was a very good meeting and a great opportunity for Trustees, members and supporters to meet and talk. It was particularly good to see new faces, and we hope they will have been inspired to further fundraising and other efforts to promote our shared cause.

Thanks to Shirley and Alastair Clark for organising the venue, and to St Winefrides for allowing us to use the facilities. Thanks to Tracy Davies and Lorraine Hall for organising the catering which was much appreciated by all.

# Advances in Neuroblastoma Research Conference Guy Blanchard

This biennial conference is the meeting of the world-wide neuroblastoma research community. Pediatric oncologists and academics presented results of recent research and clinical trials, contributing to some 220 talks over four days, with an additional 300 posters on display. It was run by Per Kogner from the Karolinska Institute, who was able to call on four Nobel Prize winners to talk about their research, each with a (sometimes tenuous) link with neuroblastoma. The conference was supported by Barncancer Fonden, the extremely well organized Swedish children's cancer foundation.

Much is changing in neuroblastoma research, with the biggest revolution in genetic screening, mostly using what is called 'next generation sequencing', the technology for which has been accelerated by the Human Genome Project. It is used to trawl through massive amounts of tumour cell DNA to look for errors compared to non-tumour cells, either detailed DNA spelling mistakes or largescale chromosomal rearrangements. DNA information, though, is only part of the story. There are various steps involved in reading gene DNA, transcribing it into RNA and translating the RNA code into functional proteins that allow cells to go about their business. Many of these steps are known to be altered in specific ways in tumour cells. Sophisticated screening is being used to identify errors in 1) the amounts of RNA, 2) the occurrence of socalled 'epigenetic markers' that are attached to the DNA or which determine how the DNA is packaged in the cell nucleus, both of which interfere with the transcription of DNA into RNA, 3) the amounts of so-called 'micro-RNAs' that selectively bind and inactivate RNAs, 4)

the amounts of functional protein. Screening efforts are being led by many groups, notably those of John Maris (Philadelphia), Javed Khan (Texas), Frank Speleman (Ghent), Ray Stallings (Dublin) and Rogier Versteeg (Amsterdam).

As a result of these screens, a bewildering number of genes, epigenetic markers and micro-RNAs have been (and many more will continue to be) found that are being expressed differently in neuroblastoma tumour cells. However, these potential targets will only be useful if they can be matched to an appropriate drug, and it remains to be seen which will make it into clinical practice. There was greatest activity in finding drugs that target MYC-N and ALK. Trials are underway testing the efficacy of inhibitors of Aurora-A kinase and mTOR, both of which are overactivated in MYC-N tumour cells.

There was a very lively session on immunotherapy, buoyed by the recent success of Alice Yu (from San Diego, who looks very like a younger and more smiling version of The Queen) who has reported an improvement in survivorship in trials for patients in remission who had anti-GD2 combination immunotherapy. Immunotherapy is beginning to be considered as a front-line therapy for some patients.

The most controversial topic at the conference was the nature of neuroblastoma 'tumour initiating cells' (TICs), the conservative euphemism for cancer stem cells. TICs have been found in bone marrow, have characteristics of undifferentiated cells, divide rarely and can seed new neuroblastoma metastases (work of the groups of David Kaplan, Toronto & Sven Påhlman, Malmö, amongst others). TICs are different from 'bulk' tumour cells that tend to be more differentiated, divide rapidly and respond to chemotherapy. TICs have many characteristics of blood stem cells and, oddly, new results suggest that they can be genetically guite distinct from cells in the primary tumour, with fewer genetic aberrations. Maybe these TICs and primary tumour cells are descended from an ancestral tumour cell

## Understanding TICs will be vital time as the cancer to preventing relapse

but have evolved apart for guite some has developed within the patient. It is possible that in

some/all neuroblastomas there is a small population of TICs within the primary tumour but this has not yet been proven, though it was reported that some primary tumours are genetically diverse. Next generation sequencing technologies looking at small sub-samples of cells from within tumours will help unravel this question.

As you can see, we are missing key pieces of information to understand what TICs are and where they have come from. Understanding TICs will be vital to preventing relapse, since it is likely that TICs survive chemotherapy in some patients. Keeping an open mind about what we might find seems to be the most important rule right now. I was pleased to see that people are beginning to look at within-patient evolution of neuroblastoma, mainly from the group of Olivier Delattre in Paris. They are finding that cells in secondary metastases have accumulated additional DNA errors compared to the original primary tumour, even in the absence of chemotherapy. Treatment regimes must allow for different tumour variants within a patient and for tumour evolution during therapy.

There was much informal discussion about the storage of tumour tissue samples in common bio-banks that would be made available to all researchers. This could be an opportunity for charities from different countries to come together to help fund.

Groups from the US, Canada, Germany and Belgium were particularly well represented, though the UK groups that came gave very interesting talks and posters. Many are past or current holders of Neuroblastoma Society grants. Susan Burchill (Leeds) spoke about simple ways of detecting 'minimal residual disease', predicting risk of relapse. Louis Chesler (Royal Marsden) discussed the development of novel therapies using murine models, while Rachel Carter from Diana Moss's group (Liverpool) spoke about reprogramming tumour cells by exposing them to the appropriate embryonic environment. Arturo Sala's (UCL) group presented various projects, including work on the beneficial effects of green tea catechins. John Anderson (UCL, talk) and Juliet Gray (Southampton, poster) both presented their latest developments in immunotherapy. There were also interesting posters from the groups of Pramila Ramani (Bristol), Debbie Tweddle and Christopher Redfern (both Newcastle).

Building on the success of this Conference in exposing research groups to the latest international research and enabling them to meet and exchange ideas, The Neuroblastoma Society is organising a Neuroblastoma Research Symposium in Cambridge on 3rd December 2010. This meeting will involve a combination of the best UK and international speakers and will draw much of the UK clinical, research and charity communities together for the first time, focused on turning new research into trials and treatment for high risk neuroblastoma.

# **Open Day at Liverpool University**

Earlier this year, Dr Diana Moss and Professor Mike White, grant holders at Liverpool University, contacted us with an offer to hold an Open Day. Arrangements were made and a party of around 20, which included most Trustees and a good showing of local members, turned up at the School of Biological Sciences on the 19<sup>th</sup> May. We were treated to a fascinating insight into the neuroblastoma research being undertaken at the University and I was personally impressed by the dedication and enthusiasm of the research workers and their willingness to explain their work to us. I'd like to send a big thank you to everyone who made the day interesting and run like clockwork.

The department made us feel very welcome and we were able to meet everyone informally over lunch. I was amazed to find that I had worked in the same university department as Professor Mike White about 30 years ago. Unfortunately talking to so many interesting people made the time fly past and I only had time for a brief look at the work displayed on the colourful posters in the centre of the room.

After lunch, several members of the department gave short talks about their work, before we were given a tour of the laboratories. Paul Losty explained the combination of both dedicated clinicians and research scientists made Liverpool an excellent centre for studies on neuroblastoma. This means that any promising ideas arising from model systems can be checked on real tumour material. He thanked all the families for donating this material at a very difficult time in their lives.

Mike White and Rachel Nelson explained how they were studying the behaviour of

tumour cells by looking for proteins known to be associated with the survival and death of cells after exposure to different treatments. We saw some beautiful images of proteins stained with different colours inside cells and by seeing where two colours/proteins coincided, a picture of which proteins were working together could be built up. Understanding how neuroblastoma cells die may help to devise methods to activate these internal processes in aggressive tumours.

We were introduced to a study conducted by Diana Moss and Rachel Carter which is testing whether the introduction of neuroblastoma cells into an early embryonic environment will reprogramme them toward benign behavior. This approach looks at the way that embryonic stem cells and melanoma cells change their 'normal' behaviour when transplanted to a different environment. At an early stage it had been difficult to get good staining of the neuroblastoma cells in order to see them clearly but perseverance and a change of approach had led to success and we were shown some impressive images of green-stained neuroblastoma cells. The group is now ready to see if, and where in the early embryonic environment, specific types of neuroblastoma cells will survive and grow. The aim is to determine ways to divert neuroblastoma cancer stem cells away from tumour formation and into benign and hence curable derivatives.

With all this information spinning in our heads, we were shown the laboratories and given a chance to ask more questions which were answered patiently. We saw proteins being separated on gels and realtime demonstration of fluorescently stained cells moving along blood vessels. Fascinating! The last port of call was the Centre for Cell Imaging which contains six specialised microscopes and related equipment worth nearly £3million pounds. It is this equipment which is used to look at the processes going on inside living cells, including what happens inside neuroblastoma cells.

One of the conditions that the Society puts on our grant holders is that they should aim to hold an Open Day during the course of their project to be attended by members and supporters of the Society. The idea of this is to help us all understand better where the research is leading and see how the money from our fundraising efforts is being spent. All these days will be advertised in the Newsletter and, based on my experience at Liverpool, I would recommend going if you can.



Above: Looking at images of stained cells Below: visitors and research teams With thanks to Awais Muhammad for the photographs



# Neuroblastoma Research Symposium

The Neuroblastoma Society is organising a Neuroblastoma Research Symposium on Friday, 3rd December 2010 at the CRUK Cambridge Research Institute, aimed at 'Future Treatments for High Risk Neuroblastoma'. The purpose of the day is to bring together in one place for the first time the three main UK neuroblastoma caucuses (the research and pediatric oncology communities and the charities that fund neuroblastoma research) to hear each other speak and to meet. The line-up of invited speakers is extremely strong, with acceptances so far from Prof. Andy Pearson (Royal Marsden), Prof. Hermann Rohrer (Hamburg), Prof. Ray Stallings (Dublin), Prof. David Kaplan (Toronto), Prof. Ben Simons and Prof. Gerard Evan (both Cambridge). Representatives from many research groups in the UK will also give shorter talks, and it promises to be a very stimulating day with many of the world's leading neuroblastoma researchers present. We hope that this meeting will help attract other researchers to the field of neuroblastoma.

Registration is compulsory but free (by email to research@neuroblastoma.org.uk stating your affiliation) and is open to researchers, pediatric oncologists and charity representatives, with a limit of 200 delegates. The costs of the day will be met by The Neuroblastoma Society with help from SPARKS, Adam's Hats and various other UK and international neuroblastoma charities. There will also be a short presentation from each charity, detailing how and when to apply for funding. If this day is a success, as it promises to be, The Neuroblastoma Society plans to repeat it every 2 years, hopefully tying in with the launch of our biennial grant rounds.

#### **Sports Report**

The last few months have been very busy with a wide range of sporting activities undertaken to raise money for the Society. Amongst them have been some truly remarkable performances. Our roll of honour so far this year includes the following: Becki Jones climbed Snowdon; Jen Lynch completed the inaugural Brighton Marathon; a team of six runners (Sean Dawson, Adam Williams, Ben Richards, Liam Brice, William Richards & Liam McGinlay) completed the Stafford half marathon and also organised a darts tournament; Pam Spittle took part in the Plymouth half marathon. The thought of all the families facing this horrible disease kept Pam going and enabled her to successfully complete this tough event.

The London Marathon is one of the Society's largest fundraising events. We have a small number of charity places and also receive sponsorship from supporters who enter the race via the public ballot.

All of our Golden Bond runners who made it to the start line successfully completed the race. They were: Vicky Turner, Lee Burrows, Andy McWhan, Iain Stevenson and Caroline Nicolaides. Caroline, who runs the Society's Befriending Scheme, injured her ankle a few days before the race but still fought her way round. She has a special thank you to her sister Helen who persuaded large numbers of people to sponsor her. Caroline's daughter Eleanor also gave a talk at school about neuroblastoma and sold cakes in her lunchtime to raise money for the Society. lain ran the Paris, Brighton and London marathons in consecutive weekends in memory of his son Ben – an amazing achievement. Jain also had to endure a live radio interview during his preparation and found that far more daunting than the



Above left: Iain Stevenson Above right: Kate, Andy & Lucy McWhan Right: Caroline, Anthony & Eleanor Nicolaides Facing page, top: Mount Toubkal team Facing page, bottom: "The Young Guns"



**Stuart Spokes** 



actual running. Andy ran the marathon in memory of my daughter Hayley as his youngest daughter Kate was one of her best friends. A huge thank you to Andy, Jo and the girls from the Spokes family.

Allan Collins also ran the London Marathon for the Society as did Dolly Jones who again managed to raise a huge amount of sponsorship money. Dolly was also brave enough to give a talk at our recent AGM about her exploits.

Charlotte Gibson, Rachael McMaster and Sally Cassidy recently completed the Bracknell half marathon. They were collared by Radio Berkshire for a live interview during the run and are now dubbed "the Maidenhead Mothers".

Another huge source of sponsorship came from the ascent of Mount Toubkal in Morocco by a team of climbers. Mount Toubkal is the 36<sup>th</sup> highest mountain in the world. The team consisted of: **Neil and Kathy Wright, Pelu and Nicky Triay, Andrew and Susan Tucker, John and** 

Tazie Isola, John and Christine Hodgson, James Cottrell, Tammy Stewart-Wilson, Sammy Armstrong, Nikki Jackson, Tanya Triay, Gerry and Frances Kelly and Charlie and Michelle Stagnetto. There is not space in this article to fully record their achievements but a full and detailed report of the ascent can be found on the group's Just Giving page at www.justgiving.com/climbingforcancer.

The Society obtained places in the Edinburgh half marathon and the team relay for the first time this year. Jenny Pringle took part in the half marathon and a team of young runners from Edinburgh Athletic Club entered the team relay. The relay team (Peter Cameron, Lauren Stoddart, Adam Jack and Lewis Renton) completed the race in 2 hours 56 minutes and were placed 6<sup>th</sup> out of 844 teams. A fantastic achievement and one which earned them first place in the "Young Guns" category for teams with a combined age of less than 100. Peter said, "We were running in memory of Sarah Thornton who died a few years ago from neuroblastoma and was a close friend of my cousin. The race was really tough as it turned out to be the hottest day of the year. Runners were looking for shade as they waited to run and the heat really sapped our energy."

A number of cycling events are taking place over the next few weeks and I'd like to wish them the best of luck: **John Foster** and his team of 6 (Wolverhampton to Lands End); **Josh Abbott** (London to





Paris); Gavin Loveridge and his friend Mat (Lands End to Hastings...stop press Gavin is now injured and has postponed until next year); Aaron Beatty, Dougie Benzie and Connor Dinsmore (350 miles from Cork, up the west coast of Ireland, to arrive in Portrush 7 days later); Alex Harris and his two brothers (John O'Groats to Lands End, in a 3-day continuous relay www.justgiving.com/The-lycra-lads).

We also have runners lined up for the Adidas British 10K in London, The Great North and Great South Runs, as well as a host of individual events during the next 3-4 months. The Big Fun Run events are due to start soon and will run through the summer and into the autumn. Check out their website at www.bigfunrun.com to see if there is an event near you and get a team of people together to run for the Society. They are open to all age groups.

Other forthcoming events include: a fundraising ball on 4 December; two golf days and a World Cup Football tournament. I would like to wish all our fundraisers, organisers and supporters the very best of luck.

If I have overlooked someone's fundraising efforts, please accept my apologies and contact me at marathon@neuroblastoma.org.uk and I will rectify this in the next issue.

If any of these stories have inspired you to do something to support the Society please get in touch.

## Fundraising continued



In December 2009 the Bishops Waltham Masonic Lodge raised a significant amount of money in memory of a special little boy-Alex Blair. Alex was diagnosed with neuroblastoma at just 15 months old and following a 2 year battle lost his fight on the 22nd August 2009 aged just 3 years. At their evening meal in December, the Lodge held a raffle, the proceeds of which have been donated to the Neuroblastoma Society. Ian West, Master of the Lodge, and a colleague of Alex's dad Gareth, said "...it just seems entirely appropriate that as I have the opportunity to assist a charity dedicated to easing the suffering of this dreadful childhood cancer and trying to find ways of curing it - then I should do." We would like to thank the Lodge and everyone involved in the evening for their support.

Gareth is also organising The Classic Vehicle Show at Marwell on 19 September in support of The Neuroblastoma Society and Piam Brown Children's Cancer Ward at Southampton General Hospital www.classicsatmarwell.co.uk.

With grateful thanks to Jon Pennells for his recent contributions to the Society in memory of his son, Reece. Jon and his new wife Lisa asked for donations to the Society in lieu of wedding presents. Jon also asked for donations from friends and work colleagues in lieu of Christmas cards.

David Battle from Surrey has sent a donation raised by the Lorica Golf Day in memory of their daughter, Sarah. Thanks to Nick Bushell, Princes Golf Club, the McGurk family and colleagues and clients from Lorica Consulting Ltd. This year's Golf Day will be held on 3 September.



Jenny White and colleagues from the Basingstoke Magistrates Court, along with their families (and dogs), pictured above, took part in a sponsored walk on behalf of the Society. Thank you!

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For an inspiring story, visit Matt Hill's page www.justgiving.com/hipster and help him reach his target. Thank you, Matt.



Nick swimmingly fundraises £3,000 ENDRASING champion Nick Morgan has recently completed another swim for charly. Nick has raised nore than £3,000 for the Naroddastoma Society for Children by swimming lengths of the Metropole Hotel swimming pool, Llandrindou, Anghun, S. "Naroddastoma is a timble cancer and none money is needed to find better medicines to help children alfected," Nick wore to the Constr Times. "The another than the service of the service We thank the Thompson family from Cumbria for the many fundraising events they have organised in memory of their son, Declan, and take this opportunity to apologise to Darren Thompson for misnaming him in a previous newsletter. Darren's wife, Julie, and his mum, Audrey, ran a tombola stall and 'decorate a tree' event at their local Christmas Tree Festival whilst Darren took part in the Tour De Furness 52 mile sponsored cycle ride where he was the first man back! Declan's cousin Callum took part in the Grizedale Forest Challenge cycle ride and aunt and uncle, Jean and Peter Morton, and cousins Carol and Fred Saunders gave donations to remember Declan on his birthday. The family would like to thank everyone for their involvement and support.

A Summer Charity Ball is being held on 10 September with proceeds going to the J-A-C-K Foundation for neuroblastoma research—see: www.j-a-c-k.org/images/ poster%20summer%20ball.pdf for more information.

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**GREAT HOCKHAM PRIMARY SCHOOL** 

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Dear Maureen

of the Neuroblastorna Society

My name is Harvey Muggridge I am lo years dd I attend a school called great hockham primary my class is called Bluebells this is for 5's and 6's. A couple of weeks ago my charss grew and sold a variety of glowers and a Sew vegetables which we sold agter school and our teacher Mrs Fowler sold the rest to a neighbour. We raised & 42.35, Mrs. Fourler asked usig any ogus had a charity that we would like the money to go towards I asked Mrs Fowler igit would like the money is go towards would be possible to go towards your society as my older sister Chloe passed away just over 7 years ago to Newroblastoma, I know my class my teacher and I would appreciate it is this letter got into your magazine.

Thank you to Harvey, Mrs Fowler and everyone at Great Hockham Primary School an inspiration to us all.

Yours sincerely Harrey Muggridge

Katie's Garden, written by Fiona Adams, is a story book about cancer suitable for pre-school children. Fiona wrote Katie's Garden after being unable to find a suitable book following her daughter's diagnosis with Wilm's tumour. Free copies are available from: www.be.macmillan.org or download a copy from the Society's website.

#### Find us on Twitter

Do you sell on eBay? Did you know you can donate a percentage of your profits to The Neuroblastoma Society? Go to the 'sell for charity' site and choose us as the beneficiary.



Find us on Facebook

# Donations

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

Ted Crancher, Colin McDonald and their colleagues on the Fulmar Alpha oil and gas production platform, run by Talisman Energy UK Ltd, in the North Sea for nominating the Society as a recipient of the funds raised through their Charity Committee.

Mrs Patricia Jacobs from Kent gave a recital at her home.

Katy and the ladies of the Caversham Inner Wheel Club had a charity lunch hosted by Mrs Joan Belcher.

David Sneesby from Bucks nominated the Society in a charity scheme operated by his company, Snowdon Tate Ltd.

Betty and Paddy Borgeat from Hemel Hempstead requested donations to the Society on the occasion of their Diamond Wedding anniversary.

Chris Ewell and APM Metals in Kent collected and recycled metals.

Mrs M P Hancock from Bournemouth requested donations in lieu of gifts to mark her 90th birthday, and also sent a donation from Mr & Mrs D Palmer.

Tony Beecroft from Essex and his colleagues at GSK Pharmaceuticals.

Mrs E Featherstone from Cambridge sold logs from a fallen tree in her garden.

Mrs Connie Riddle from Troon made a welcome donation.

Hector and Judy Fraser from East Yorkshire sold some redundant gardening equipment.

Jill Howell from Littlehampton organised a Hand Bell Concert at her local church.

Ms Mary Cheesewright from Chelmsford donated her car to Giveacar Ltd which benefited the Society — for more information, see www.giveacar.co.uk.

James McQueen from West Cheshire College in Chester sent in a donation raised by the Public Services Students.

Mr Liam Holt of The Portsmouth City Band nominated the Society to receive a donation raised from one of their performances and sent in by the Treasurer, Mr Kerren Hoade.



Joan Brown, after many years tirelessly packing the newsletter, has now retired from the job. We would like to express our appreciation for all Joan's hard work and efforts on behalf of the Society and wish her all the best for the future.

Tracey Reed and staff of Allegro MicroSystems Ltd in Surrey, raised as part of their monthly charity collection.

Donal and Lorraine Fleming from Middlesex from their charity accounts.

Ruth Jones and the Salvation Army Citadel in Leighon-Sea.

Julien R Triay from Gibraltar raised through the Toubkal Appeal.

Mrs Daphne Roth from London on behalf of her sister.

Ms Jill Gibson from Sheffield sent a welcome donation.

Mrs J Whalley and friends, sent in by Julie Thompson from Cumbria.

John, Jill, Laura and Greig Smith from Jersey, in memory of Mrs Hilda Le Behan.

Jill and Richard Webster from East Sussex, also in memory of Mrs Hilda Le Behan.

Mr Edwards, staff and pupils of Ysgol Penmorfa CP School in Denbighshire from their Harvest Collection.

Emma Urquhart and members of the Teagues Bridge Pre-School in Telford for taking part in a sponsored walk to their local National Park in memory of Kyle Beddoes.

Mr Ron Gandolfo, Headteacher, Lingfield Primary School in Surrey, sent in a donation raised by three pupils who sang and danced in memory of a former pupil.

Angela White and her daughters Sadie and Mica from Northampton took part in the Milton Keynes Fun Run.

Andrew and Linda Bernard took part in the Grim Challenge 2009 race.

Mr A Roxburgh from Broxburn took part in a local Big Fun Run.

In memory of his nephew Jake, Mike Hall from Surrey is taking part in a sponsored sports event for every month of this year. See

www.keeponrunning.tumblr.com to update on Mike's progress. David Pearson Management Ltd helped Mike along with a donation for the Triathlon he completed last year.

Dean Porter from Felixstowe, partly raised through a Live Band Night at the football club he manages and by Austin Jones' participation in a half marathon.

Nicky and Anthony Marsland from Cheshire sent a donation in memory of their son Jacob, raised by the Pryers Hayes Golf Club near Chester and Club Captain Bob and his wife Julie.

Rosemary Harding from Hampshire sponsored Dolly Jones in the London Marathon.

David Bolton from the Wirral won a Kick Boxing World Title event in Italy in 2009 and donated sponsorship to the Society.

Helen Butler from Bolton was inspired to donate by neuroblastoma patient Luke Chadney.

Bethany Shaw and Jason Rose from Gloucester who ran in the Cardiff Half Marathon last October.

Dolly Jones, who ran the London Marathon for the second time (see AGM report on page 4).

Hassan Choudhury from London, raised through a World Cup raffle.

Ferguson Bricknell Solicitors from the estate of the late Joan Skidmore.

Adrian and Kary North in memory of their son Alexander Ronnie North.

David Atkins and Jessica Hutchings from Andover in memory of their granddaughter, Emily Atkins, on her 10th birthday.

Miss Louise Sutherland from Glasgow in memory of Grant Sutherland.

Lorraine Hall from Buckinghamshire and the Buckinghamshire County Council who raised money at a Quiz Night in memory of Lorraine's son Jake Hall.

June Drennan from Glasgow, to remember her grandson Grant Sutherland on his 16th birthday.

Mrs Margaret Farr from Shoeburyness for collecting loose change in memory of Tom Willson.

Mrs Sarah Weber, Headteacher, and members of staff of Batheaston Primary School in Bath, in memory of Amelia Price.

Helen and Bob Norman from Northampton who held a Quiz Night in memory of their daughter Charis.

Cherry and Guy Blanchard from Cambridge who asked for donations to the Society in lieu of gifts at their wedding, in memory of their son Locke.

Beverley and Garry Wright and Mrs I Warner from Kent in memory of Christopher James Wright.

Mrs J Cole from West Sussex in memory of her grandson Josh Kadan, on his 20th birthday.

David and Sheila Rawlings from Warwickshire from the estate of Sheila's sister, Doreen Parker, in memory of Doreen and their grandson Craig David Ashby.

Kevin and Eileen Murphy from London in memory of their grandson Michael O'Donnell.

Amy Heness from Hartlepool in memory of her grandson, Matthew Jakeman, on his 12th birthday.

Sara Morgan from Cardiff in memory of her sister Lizzie.

Rob and Dawn Muggridge from The Puddledock Farm Camping & Caravan Site in Norfolk in memory of their daughter Chloe Peaches, raised from their Society collection box and through their Easter Raffle and Easter Egg Hunt, with help from Sonia and Colin and Janet and Ann.

Julie and Darren Thompson and mum-in-law Audrey from a Quiz and Coffee Morning, in memory of Declan Thompson.

Mrs Ann Greenfield from Great Wakering in memory of Tom Willson.

Sue Leaver from HMRC in Southend-on-Sea, in memory of Tom Willson.

Mr JS Garlick from Holmfirth in memory of his daughter Janet.

Elizabeth Aston and mums from The Buzz Club in Bath for organising a Jamie Oliver Party, in memory of Amelia Price.

### Please send donations to: The Accounting Officer 189 High Street Great Wakering Essex SS3 oEA 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 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	Mr Des Fordham, 22 Norwich Street, Cambridge, CB2 1NE annualdraw@neuroblastoma.org.uk	
Befriending	Mrs Caroline Nicolaides—befriending@neuroblastoma.org.uk	
Collecting Boxes	Mr Laurie Bradshaw, Orchard House, Bulmer, York, YO6o 7BL collectingboxes@neuroblastoma.org.uk	
Donations	Mrs Maureen Peters, 189 High Street, Great Wakering, Essex, SS3 oEA donations@neuroblastoma.org.uk	
Monthly Draw Club	Mrs Michelle Stephenson, 9 Reservoir Road, Erdington, Birmingham, B23 6DA	
Newsletter Packer	Mrs Maureen Stevenson	
Parents' Booklet	Mrs Joanne Pennells—hospitalbooklet@neuroblastoma.org.uk	
Pin Badges	Ms Lorraine Hall—IoI.hall@ntlworld.com	
Stamp Appeal	Appeal Mr & Mrs C Wade, 13 Longacre Road, Cressing, Braintree, Essex, CM77 8HG	
Website Co-ordination	Mr Dennis Bignell—society@talktalk.net	

# SOCIETY HELP LINE FOR INFORMATION AND GENERAL ENQUIRIES 020 8940 4353

www.neuroblastoma.org.uk