

2011 Neuroblastoma Research Symposium and SIOPEN AGM



Peppy Brock, Andy Pearson, Keith Holmes and Ruth Ladenstein

The SIOPEN AGM meeting was held on 12-14th October at the Institute of Child Health, London. This meeting was brought to London by our former long-standing Medical Trustee, Peppy Brock (Great Ormond Street Hospital), who is now President of SIOPEN (the European neuroblastoma clinicians group). The first two days were devoted to the business of SIOPEN, formulating and managing European-wide trials of new treatments. The third day was the 2011 Neuroblastoma Research Symposium, the sequel to The Society's 2010 Cambridge Symposium, this time co-produced by us, SIOPEN and the UK CCLG. The Society was a major sponsor of the SIOPEN AGM, and met additional costs of the Symposium, to which Cancer Research UK and SPARKS charity also made contributions. In this

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SPRING CONFERENCE AND ANNUAL GENERAL MEETING

Saturday, 28 April 2012

The Society's Spring Conference and Annual General Meeting will take place on Saturday, 28 April at St George's Church, Bloomsbury, beginning at 11am.

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Editor's Note

The opening of a new year and I am saddened at the thought that another 100 children will be diagnosed with neuroblastoma. 100 children, 200 parents, many more sisters, brothers, grandparents, aunts, uncles and friends, all facing the prospect of fighting this devastating disease.

The opening of a new year and the closing date for applications to our Grant Round. The researchers and clinicians hoping to receive the funding that will enable them to continue their search for better treatments and hopefully a cure for neuroblastoma.

The opening of a new year and the making of resolutions. What will yours be? Those new 100 children and those still fighting need us more than ever.

So, let's challenge ourselves again—do something we've never done before—run a race, shave our head, bake a cake, climb a mountain, sit in a bath of beans—you'll think of something. And then we can help those researchers on their way.

You really can make a difference.

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 Spring Newsletter
DEADLINE 29 February

Meet the Trustees—Yvonne Boyd, Secretary & Grants Administration

I joined the Neuroblastoma Society in 1986 when my niece Eleanor was diagnosed with the disease at the age of 9 months. My sister was going up and down to London with her daughter to Great Ormond Street

Hospital to see Dr Jon Pritchard and his young colleague, Dr Penelope Brock. Despite intensive treatment both at Great Ormond Street and the local hospital in Brighton, Eleanor lost her battle with the disease when she was 18 months old. For several years, my sister and I came with our children to the Society's AGMs organised by Janet and Neville Oldridge at the Institute of Child Health.

After a period when other things in life seemed to get in the way and we didn't make the AGMs, in 2009 we started attending again and I thought maybe I had reached a point where I could do something positive to help. I offered to help with running the grants round for the Neuroblastoma Society but suddenly found myself succumbing to the Chairman's persuasive powers and not only agreeing to become a Trustee but also to take on the role of Secretary. My main functions as Secretary are to organise the Trustee meetings and



support the Chair and Treasurer in running the Society. I still feel I have a lot to learn despite getting plenty of helpful advice from Dennis Bignell, the previous incumbent. As my background is in biomedical research and its management, I try to

help Guy Blanchard and the other Trustees on the science and research issues that arise as well as running the grant round. The grant round takes more time than the Secretary's job as the Society takes great care to make sure we get the best advice available on which grant applications to support with the hard-won money raised by all our members. The grant round is run electronically and each application is sent to about four expert reviewers as well as the six members of the Scientific Advisory Board.

I moved around a lot during my childhood and again during my higher education and the early stages of bringing up my family. We moved to Oxford in 1978 and I worked locally in various scientific research laboratories for over 20 years. Eight years ago, I was lucky to be offered the position of managing a large research programme in a government department. The experience this job gave me has been really useful in managing the

Neuroblastoma Society's grant round. I am beginning to understand the scientific complexities of neuroblastomas and the value and nature of the research studies that are supported by the Society. Research is always a high-risk business but it's really pleasing to see that the Society seems to have been very wise in the past as many of the research projects we fund are contributing directly or indirectly to improved therapies for the children we all care about so deeply.

The most important calls on my time are my family, particularly my immediate family - I have a son and daughter, and four gorgeous grandchildren. With 3 brothers and 2 sisters between us, we have a large extended family of 11 nephews and 1 niece. By the time we include spouses and partners, it means that we usually meet in a London Park rather than someone's house for our annual summer get-together. I also spend some time gardening – enjoying what fruit and vegetables I manage to protect from the ravages of the local wildlife. I manage to do a bit of cycling to keep fit, but I don't get round to any other sport other than swimming on holiday. I am amazed at how little "free" time there is now I am retired. I live in hope that all I need to do is get better organised and somehow all those projects planned for retirement might somehow not only get started but actually get completed. Any advice on this gratefully received!

People and Jobs

Trustees

I have sometimes said that the main job of the Chairman of Trustees seems to be to find new Trustees so I am delighted to say that we have recently appointed three new Trustees. Before introducing them, I must express my thanks and those of us all to Stuart Spokes, who is stepping down as Trustee responsible for sports events (especially marathons). These sponsored events have continued to be our single most important source of fundraising, and under Stuart's stewardship the amount raised and the range of events covered have both increased. Professional and family commitments now mean that Stuart is stepping down, with our thanks and best wishes – and we take seriously his wish to come back and get involved again some time in the future.

Tep Crowder is stepping into Stuart's shoes as our new Trustee for sporting events. Tep's first major exposure to the Society was as a guest speaker at our Spring Conference this year, where he spoke movingly and eloquently about his family's experience of dealing with the diagnosis and treatment of neuroblastoma. Our sponsored sporting events are in good hands, and I anticipate Tep looking out for new opportunities and challenges for our runners, swimmers, cyclists and I encourage you to contact him with your ideas!

Ben Sharp is another parent bringing his energy and expertise to the Society as Trustee for corporate and charitable trust fundraising. He has already demonstrated his effectiveness by working on behalf of Dr Kate Mitchell to organise the UK contribution to financing the operation of the Europe-wide clinical trials database run by SIOOPEN. Ben works as a development manager for BAA at Heathrow, but has taken extended leave while his son is under treatment. If you know of or have connections to companies, charitable trusts and foundations, and organisations such as Rotary clubs, and think they may be potential donors, I am sure Ben will be pleased to hear from you.

Natalie Cramp is our third new Trustee, taking up a newly defined role in co-ordinating our volunteer efforts. We expect this to involve maintaining a more active engagement with volunteers and supporters, developing relationships and hopefully stimulating them to stay involved in fundraising and other Society activities. Natalie works for management consultancy Deloitte, and is currently on a long term assignment with the London Organising Committee of the Olympic Games, where her responsibilities include managing the volunteer workforce.

A very warm welcome and 'thank-you' to all three of our new colleagues – we look forward to working together for the good of the Society and its cause.

We would also like to extend our thanks for their support to Joanne Pennells and Lorraine Hall as they stand down and to welcome Eileen Rowe and Mary Waterhouse as Parent Booklet co-ordinator and Pin Badge co-ordinator respectively.

Help needed

We are still looking for volunteers for two important roles with the Society, both to start as soon as possible. We need someone to take on the Accounting Officer work currently performed by Maureen Peters: this involves receiving, banking and acknowledging donations, and reporting them to the Treasurer. It doesn't require accounting or other financial qualifications, just a few hours a week, and offers the opportunity to make a major contribution to our work while coming into contact with lots of Society supporters.

We also need someone to take over the Annual Draw that Des Fordham has run for many years. This involves organising prizes, printing and distributing tickets, collection of stubs and money, and the actual Draw itself (normally at the Spring Conference). The Annual Draw not only raises a significant amount of money but is also one of the ways that we keep in touch with members and supporters, so we are very keen to find someone to help.

Stephen Smith, Chairman

short report, I will first highlight selected aspects of the SIOOPEN meeting before returning to the Symposium below.

Much time was devoted during the **SIOOPEN AGM** to the current high risk trial. The first result from this trial was presented in full, describing the improved survivorship with BUMEL compared to CEM as front-line chemotherapy.

We have reported on this in more detail previously. The current comparison underway in this trial is the immunotherapy randomisation, comparing anti-GD2 vs anti-GD2 + IL-2. Recruitment of patients was reported to be good, meaning that the trial should complete along expected time-lines. Issues with IL-2 toxicity were discussed, and a continuous infusion Phase I trial is currently open in centres in Germany and Austria. A new 2-arm randomisation for children that relapse, for whom there have been limited options, was decided upon. This will introduce targeted mIBG therapy to the high risk trial for the first time, in a comparison with MELBU. It is hoped that this targeted mIBG, along with anti-GD2 immunotherapy will soon be offered as front-line therapy for an ultra-high risk group of patients, for whom current treatments are inadequate. First, however, further work is required

on identifying which patients are ultra-high risk.

The UK presence and involvement in SIOOPEN is significant and appropriate, given the fundamental importance of SIOOPEN trials to UK children with neuroblastoma. For example, the energies of Susan Burchill (Leeds), Andy Pearson (Royal Marsden) and Mark Gaze (UCL) were particularly impressive in, respectively, driving methods to predict disease progression from the monitoring of disease in blood samples; identifying the next generation of new treatments; and advocating the introduction of targeted mIBG therapy. On her retirement, Jan Kohler (Southampton) gave an excellent Plenary talk about past and current efforts to usefully classify neuroblastoma disease so that treatment can be tailored appropriately. Her clarity of thought and presentation will be missed.

Key personnel for planning, monitoring and closing trials are statisticians, who ensure that questions are posed and data collected in the right way so that conclusions drawn will be valid. Within SIOOPEN, Ruth Ladenstein and co-workers in Vienna have been responsible for this. As SIOOPEN grew from a largely self-organised collection of European clinicians, the outstanding work in Vienna was vital to and underpinned



Daniel Morgenstern, Yvonne Boyd
and Guy Blanchard

the reputation and growth of SIOPEN. This success has resulted in a large SIOPEN database of patient information, which ought now to be rapidly analysed by groups throughout SIOPEN so that treatment decisions can be better informed. There is also now an opportunity for more diverse input into the formulation and monitoring of trials from statisticians from other countries, to find innovative ways in which new potential treatments are introduced.

Delegates were given a taste of English culture during the day by the Bootham School Choir, that included a former patient of Peppy Brock, and by three excellent dance pieces by children and youths at The Place in the evening, both organised by Susan Hay.

The meeting as a whole was a great success, thanks to the hard work of many people, guided by Peppy Brock and ably assisted by Daniel Morgenstern (ICH).

On the third day, over 200 UK and European academics, clinicians and charity representatives attended the **2011 Neuroblastoma Research Symposium**. Most UK academic groups with interests in neuroblastoma were represented. Three sessions, on immunotherapy, gene and micro-RNA signatures and new treatments each featured excellent international speakers and lively discussion. Both published work and work in progress were presented on developments towards improved treatment for high risk neuroblastoma. 32 posters were presented by younger researchers covering many different aspects of neuroblastoma. Rogier Versteeg (Amsterdam) and Peter Ambros (Vienna) chaired a very successful Plenary Poster Session after lunch, selecting 8 posters for short oral presentation, which gave students an opportunity to present to the whole meeting.

A scientific write-up of the Symposium is currently being drafted for submission to a scientific journal, helping to raise the profile of neuroblastoma as a focus for research. I will adapt a lay report from this scientific write-up and circulate this as a 'pdf' to parents via charities, and

make it available for download from our website (<http://www.nsoc.co.uk/symposium2011.html>) by the end of January '12.

Delegate responses to feedback questionnaires were very positive. The next Symposium that the Society will run will be in Autumn 2013, when it will hopefully again be linked to another paediatric oncology meeting. The Society has run the 2010 and 2011 Symposia to facilitate connections within what was quite a disparate UK neuroblastoma research community, and between UK academics and clinicians. It was clear from this meeting that there is a healthy appetite for a Europe-wide meeting. Indeed, much research into neuroblastoma is now internationally collaborative, and UK groups need to be involved in these collaborations.

Guy Blanchard

Trustee Business

DES/OMS workshop

At our last Trustee Meeting in November, it was agreed that the Society would extend a 'meeting support grant' to the International Opsoclonus-Myoclonus/Dancing Eye Syndrome Workshop which is due to take place in Oxford in February.

OMS is an immune-mediated disorder which in around 50% of cases is associated with a, usually relatively benign, neuroblastoma. Around 2% of

children with neuroblastoma will have OMS.

DES/OMS begins with chaotic eye movements, usually in children under 3 years, and is accompanied by jerky movements of limbs and trunk, with poor balance and severe incoordination. The onset, can be rapid over a few days, or gradual over several weeks. Children in the untreated phase of the illness are usually inconsolably distressed, with very disturbed sleep.

The Workshops were set up in 2001 by Jon Pritchard and Peter Beverley and are held on alternate years. They have become the single main focus for international discussion on this rare but devastating condition. Invited participants include paediatric neurologists, oncologists and immunologists and neuropsychiatrists from the UK, Europe, Israel and the USA and also a small international group of parents. Over the last 10 years, the Workshops have made a substantial impact in promoting and facilitating progress in research into DES/OMS.

A lay write up of the 2012 Workshop will be published in a future edition of the newsletter.

If you would like more information about DES/OMS, please visit the Dancing Eye Syndrome Trust website: www.dancingeyes.org.uk. They also have a Support Group on Facebook—<https://www.facebook.com/groups/48271703613/>.

Research Update

Professor Deborah Tweddle, Northern Institute for Cancer Research, Newcastle, updates us on her Society-funded research.

Differentiation of human embryonic stem cells to sympathetic neurones: understanding the pathogenesis of neuroblastoma.

This one year 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.

Here at Newcastle University's Northern Institute for Cancer Research we have been trying to set up a new model of normal sympathetic nervous system differentiation using human embryonic stem cells.

Neuroblastoma originates from cells in the embryo called neural crest cells which go on to form the sympathetic nervous system. By modelling the normal development of the sympathetic nervous system we hope to understand more about how neuroblastomas develop. Using two human embryonic stem cell lines we

have now generated neural crest-like cells and cells which have markers of sympathetic nerve cells. We are currently characterising these cells further and will then compare them with neuroblastoma tumours to determine what the differences are and what genetic changes are needed to make the cells cancerous. By doing so we will learn more about the origins of neuroblastoma, how it develops and possibly discover new targets for treatment.

Subscriptions

Annual subscriptions are now due. If you pay by cheque please send it (payable to The Neuroblastoma Society) to our Membership Secretary—details on page 2.

Why not consider setting up a standing order? Forms can be downloaded from our website, or contact any Trustee. Or you can give regularly through our Justgiving (<http://www.justgiving.com/nsoc/Donate>) or MyDonate (<https://mydonate.bt.com/donation/donation.html>) sites, helping to reduce our administration costs.

Subscriptions cost £10 for a single person, or £17 for a couple although higher donations are always appreciated. Membership fees are used for the administration of the Society, with any surplus being used for research.

We thank you for your continued support.

ICCCPO (icccpo.org)

The International Confederation of Childhood Cancer Parent Organisations –ICCCPO—was set up in 1994 and is an umbrella organisation currently representing 148 parent organisations for childrens’ cancer in 81 countries. Its vision is to be recognised worldwide as the body representing families of children with cancer ensuring that children receive the best possible care wherever they are in the world at the time of diagnosis and beyond. Its mission is to share information and experiences through an international network of parent support groups and survivor networks with the common goal of providing a voice for the needs of children with cancer and their families and advocating for increased awareness of childhood cancer at both a local and international level.

Their objectives include:

- To develop an international network of parent support groups
- To provide assistance and guidance in the establishment of new groups
- To provide parent organisations with information about the disease, treatment and effects in non-medical language
- To provide forums, events and opportunities for members to meet
- To encourage the development of survivor group networks

CCPA (childcancerparents.org)

The Childhood Cancer Parents Alliance (formerly the National Alliance of Childhood Cancer Parent Organisations) is a union of almost 40 parent run organisations who share a mission to improve the lives of families affected by childhood and adolescent cancer.

They advise families on grants, holidays, benefits, telephone help lines, information booklets and direct them to charities that focus on individual cancers.

They are a national representative voice for its member groups. Working with local, regional, national and international agencies, they promote awareness, support, research and advocacy that brings best possible care for all children, teenagers and young adults with cancer and their families. They represent the views of families on various Department of Health/NHS working groups including the National Institute of Clinical Excellence (NICE), Children’s and Young Person’s Cancer Services and Cancer 52, a consortium of rare cancer organisations.

The CCPA also works closely with SIOPEU and World Child Cancer and is the UK representative at ICCPO which aims to improve research, treatment and services for children with cancer no matter where in the world they live.

RUNNING HOME FOR ALEX –

By Ben Sharp

Children's Hospital



My son Alex has been treated at the John Radcliffe hospital in Oxford since his neuroblastoma diagnosis in May 2010, and I decided to run from hospital to home as a fundraiser. Not on the spur of the moment you understand - it's 35 miles on a route which avoids running along the hard shoulder of the M40. I timed the run to coincide with the end of Alex's in-patient treatment in September 2011, and ordered some decent weather.

I received amazing support. A friend who runs a PR company handled all the publicity and we were covered by the local paper and radio station. My village and friends all got well behind me, helped by me leafletting all the local hotspots and nagging the readers of my weekly blog. The fact that the journey was so personal and

significant to our family, and the timing of the run, really helped. Plus the fact that it is quite a long way.

The day of the run went really well. A friend drove a support car, loaded with bananas and energy drinks, and two other friends ran with me in relays for the 6 hours of the run, acting as my waiters and minders. The weather was perfect – still, overcast, mild, dry. Friends from my village came to run with me 8 miles from home, and the numbers grew as we got closer until I was leading a small procession of runners and cyclists into our home village. There we were met by a crowd of over 100 friends, family and neighbours for the final few hundred yards, ending with an impromptu street party outside our house, fuelled by plenty of bananas.

Even better was the fundraising. Loads of amazingly generous sponsors, many of whom I didn't know but who had heard about the run through the grapevine, enabled me to raise over £19k from my Run Home. Almost enough for a lap of honour, but not quite.....



Fundraising Stories

Great North Run and the Junior Mini Great North Run

Kathryn and Jamie McDermott from County Durham, have sent a marvellous donation raised through sponsorship of their friends who completed the Great North Run. Their son James ran the Mini Event of the same race completing the 1 mile in 8 minutes and leaving mum standing! James was diagnosed in June 2009 with stage 4 neuroblastoma. He has been in remission a year now and long may it continue! Jamie and Kathryn McDermott are very proud of James' achievements and determination. It is



lovely that he is well enough to compete in the race, and that he very much wanted to take part. He has received wonderful support from family and friends, and has raised a fantastic £1,733.50 for the Society in his own right. "Well Done" everyone.

Table Top Sale

The Matthew Russo Foundation and the Neuroblastoma Society held a table top sale at St Bernadette's Church in Crawley in November. It was a great day with local business people hiring tables to sell products which included jewellery, greetings cards, crafts and gifts along with a chance to benefit from a range of holistic and beauty treatments.

The turnout was fantastic with approximately 120 people coming along to show their support for both organisations. The event came from an idea from friends Julia Stevenson and Bridgette Russo who had talked about wanting to raise money for these fantastic organisations. It took a lot of organising and hard work but it paid off as just over £1000 was raised!

Thanks to everyone who helped and came along on the day.



The Great Wall Challenge

Liz Millington has raised over £2,300 by taking on the Great Wall Challenge. Here is her account of the trip.

Well, I DID IT! No blisters either - I now love my boots!

This seems a perfect time to summarise the last year as 12 years ago today Harry lost his battle with neuroblastoma. Whilst I'm fit and able to do so I will continue to raise funds in the hope that one day someone will find a cure for such a horrible disease. Whilst trekking I had a picture of Harry attached to my back - my reasoning was if the going got tough then I'd take a look at his smiling face, think about what he went through and then get on with it! It worked but I really don't want any other parent to do a trek in this way - I want them to be able to go home and tell their child all about it and not just have photos and memories. His picture reminded me why I was in China.

China - what an amazing place! It certainly exceeded my expectations. The scenery was stunning, the photos really don't do it justice. The trekking was hard going but with my friend



Leah by my side we laughed, cried and sang our way along that wall!

I was fortunate to be amongst a wonderful group of people who all had their own reasons for doing the challenge, their stories were inspirational.

I'd like to say thank you to everyone who has supported me through this adventure - I really couldn't have done it without you.

My biggest thanks are to Mike, George, Grace and Edward - my wonderful family. They have been so supportive and made it possible for me to go to China and enjoy every bit of the experience. I love you all xx

Liz was also invited to talk about her chosen charity on one of the evenings during the trip. Not surprisingly, most had not heard of neuroblastoma or the Society so Liz was able to inform them of our work. Thank you, Liz, for your support in memory of Harry.

Fundraising Stories

Taking to the Skies!

Michelle Lindup sent a wonderful donation in memory of her niece Ruby Lindup who sadly passed away on the 13th December 2008 after a brave fight against neuroblastoma.

The donation was raised last August through sponsorship when a group of very brave people did a Parachute Jump, to raise money for the Society.



Pub Auction

Nick Hastings landlord of The Plough Inn in Northampton, held an Auction to raise funds for the Society, which was attended by two of our representatives. Thank you to Nick and all the patrons of The Plough Inn, and everyone who attended or supported the event.

Golf Day

Once again we thank David Battle and his colleagues at Lorica for organising another very successful Golf Day raising a substantial sum for the Society. Thank you to everyone who took part.

Dancing Ghosts!

The children of the DancingKidz dance school completed their annual halloween sponsored dance for the Neuroblastoma Society and managed to raise a massive £1017.16. There must have been some tired ghosties that night! Thank you to Sharon and all the children at DancingKids and also to the Bank of America who have matched the donation.

London to Paris by bike

Debbie Beevor sent a marvellous donation raised by her 21 year old daughter Sarah, who completed the London to Paris Cycle Ride, in memory of her sister Hayley O'Brien, who sadly lost her brave fight against neuroblastoma in October 1993 when Sarah was only three years old. After all this time Sarah, who claims not to be particularly athletic, remained determined to do something for the Society in memory of Hayley. Well done Sarah, a loving tribute indeed, and thanks also to everyone who sponsored you so generously.

Sky Dive

Kevin Welch, a friend of Kathryn and Jamie Mcdermott from County Durham, also took to the skies for the Neuroblastoma Society. He took part in a sponsored sky dive in September and raised £420.50. We thank Kevin for his support and to all who sponsored him.

Christmas Cards

Very many thanks to everyone who bought Society Christmas cards. The response was so good, we have now sold out of every design enabling us to have many new designs next year. Not only does the sale of cards raise much needed funds for research but also spreads awareness of neuroblastoma to those who may otherwise not have heard of it.

Thanks also to Margaret Sutherland, Alison Scoon and Lynne Gardner who sold cards on a 'sale or return' basis.

Margaret would also like to thank Celia and John and Christina and Joe for all the help they gave her at the Glasgow Charities Fayre.

JustGiving Pages—our thanks to..

Zoe Richardson for running the Standard Chartered 10K in Singapore for the Society and for Alex Sharp. Zoe's fundraising has now exceeded her target.

James and Andrew McCarthy for running the Barns Green Half Marathon in October for the Society and for their nephew, Matthew, and raising a substantial sum.

Manasi Nandi who ran the Great South Run in 1hr 46m and has doubled her fundraising target.

Katie O'Connor for running the Great Birmingham Run.

Ben and Lara Polati who celebrated the third birthday of their son Giacomo who is being treated for neuroblastoma.

Andrea Watson and Miriam for running the Dublin Marathon in memory of Katie McKnight.

Kevin and Juliette Abrams for cycling the 'Way of the Roses'.

Samantha Collins, Debra Newell, Hubert Clarke and Stuart Lockie for taking part in the 'Rower's Revenge'.

Marc Whiting for running the Ipswich Half Marathon.

Steve Watts for taking part in a cycling event in the French Alps.

9 year old Casey Jones for climbing Ben Nevis and wearing out her mum and dad!

Rob Owen, Trevor Chanter and Peter Atkins for taking part in a variety of cycling events.

MyDonate fundraiser....

Good luck to Mark Stone who is preparing to run the 2012 Chevron Houston Marathon in a few days time. Mark tells us:

"The Houston Marathon is an annual event, held in January. ... Mercifully, the course is quite flat and only slightly boring. 2012 is the 40th anniversary of the event and ... it is also the final time-trial for the US Olympic Team - who are literally quaking in their Nike Air Pegasus at the thought of lining-up against STONER."

Help him reach his fundraising target here: <https://mydonate.bt.com/fundraisers/markstone1>.

Thank you Mark!

Geraint Jones Benefit Year



We would like to send our thanks to Geraint Jones, England and Kent cricketer, for choosing the Society as one of the beneficiaries of his Benefit Year. We look forward to hearing about upcoming events.

Farewell

It is with sadness that we bid a fond farewell to Maureen Peters, our Accounting Officer.

Maureen took up this job in June 2005 and has, with dedication, enthusiasm and compassion, written hundreds of wonderful thank you letters to our supporters—many of whom have commented on their thoughtfulness.

Maureen's life was touched by neuroblastoma when her grandson, Tom, was diagnosed with the disease in the late 1990s. Sadly, Tom died in 2002. Maureen worked at HM Revenue & Customs until her retirement and they regularly raise funds for the Society in Tom's name.

We send her our thanks and every good wish for the future—and hope that she will enjoy her 'proper' retirement!

Legacies

The Neuroblastoma Society wishes to acknowledge a very generous legacy from Diane Green of the Isle of Wight, who passed away in November 2010. The bequest was made in memory of Kerry-Lee Green who was diagnosed with neuroblastoma in 1998 and sadly lost her battle with the disease in April 2000. Our thanks and condolences to the Green family.

Leaving a Legacy

If you would like to follow Diane Green's thoughtful example, a really excellent way of supporting the Society's work is through a legacy in your will. You will be supporting a cause which will bring benefits to seriously ill children for many years into the future.

But do consult a professional for help with writing your will to make sure your wishes are fulfilled in the way you intend.

www.remembercharity.org.uk is a source of helpful advice on all aspects of writing a will.

Leave a gift to us in your will and help us continue the search for a cure for neuroblastoma.

Donations

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

Mrs K Beacham from East Sussex, in memory of Lisa Quirk.

Mrs Ann Greenfield from near Southend-on-Sea, in memory of Tom Willson, who would have been 15 years old on the 9th September.

Kevin & Eileen Murphy from London, in memory of their beloved grandson Michael O'Donnell.

Andy Grigg, Honorary Treasurer of Walmer Cricket Club in Kent, from their involvement with The Lorica Charity Golf Day held at Sandwich Town Cricket Club.

Mrs J B Williams from Hertfordshire, to sponsor Bill Sharp when he takes part in the 5k Fun Run in Victoria Park in London. Bill's grandson Alex was diagnosed with neuroblastoma in May 2010 and is currently being treated at the John Radcliffe Hospital in Oxford. Bill, who comes from Rickmansworth, has sent further donations which sponsor him.

Mrs Daphne Roth from London, from the sales of her handmade cards, jams etc.

Chris Ewell from Kent, who received a great deal of help from Kelly Ripley and Rhiana Hunt both aged 12 years, from collecting waste metal to raise funds for the Society.

Mrs Eileen O'Brien from Hertfordshire in memory of her lovely granddaughter Hayley.

Mr & Mrs North from West Yorkshire in memory of their dear son Alexander who they sadly lost to neuroblastoma 15 years ago at the age of 5 years.

Frances & Julian Worsley from Kent, in memory of the late Robin Archbold.

Rona & Ken Nicholas from Port Talbot, in memory of their beloved Grandson Rhys.

Mrs C Bateman from Solihull, to support her great nephew, who is currently undergoing treatment for neuroblastoma, much of which is taking place in Switzerland and Paris.

Mrs C Kaura from Hertfordshire, to support the work of the Society.

The Trustees of Miss W H S Wallace's Settlement Trust sent another marvellous donation.

Mrs Janet Davies from Chorley, from sponsorship for running for the Society in The Great North Run in memory of her son Rhodri who she sadly lost to neuroblastoma in 2003. Part of the donation was raised by Janet's work colleagues who organised a Cake Sale and Second Hand Book Stall, and the Media Team are running a feature in the Council Newsletter using posters about the Society and our web-site to raise awareness of neuroblastoma.

Mrs Wendy Clark from Dorset, in memory of her nephew Benji Stafford, who she sadly lost to neuroblastoma in 1988.

Donation in lieu of flowers for the late Mr Herbert Edgar Martin from Kent.

Ben Steppel from Kent, from a fundraising event held by his Mother and Father-in-Law, in memory of young Jaimee Mcguigan, who sadly lost her brave fight against neuroblastoma in July 2010. Ben and his family hope to hold further fund raising events in the future.

Ian Sutherland from Kirknewton sadly lost his dear wife Mary at the end of September. Mary was a regular supporter of the Society as are Ian's brother and his wife, Ronnie & Margaret Sutherland, so it was thought appropriate to have a

collection for us at Mary's recent funeral. The loyal support from the families is in memory of young Grant Sutherland.

Mr & Mrs E Taylor who have now moved to Great Dunmow in Essex, to fund the work of the Society.

Mr J Drummond from West Bergholt in Essex, in memory of Sam Wade.

Mishcon de Reya in London, as part of their charitable giving commitment, to support the fund raising by their staff, in respect of Miranda Dodd and her son Alex. Claire Broadbent requested that the Society was the charity to benefit from their latest fund raising events.

Ian Parsons, Treasurer of St. Michaels Church PCC in Oxfordshire. The PCC supports a number of Missions and Charities, and this year have chosen to support the Society for Ben Sharp's "Running Home for Alex" event.

Tracy Davies & Lorraine Hall from Buckinghamshire, from the Annual Quiz Night that they hold to raise funds for the Society in memory of Jake Hall. These events have become so popular and so successful that they are thinking about holding them twice a year.

Mr G Medler from Ashford in Kent, asked for donations for the Society in memory of his father the late Mr Eric Medler.

Mr M Champion to fund the work of the Society.

Mrs Beverley Wright from Kent, who is a Beaver Scout Leader of the 26th Medway Towns Beaver Colony. The Beavers had to do good turns at home for one week and collect money for each good turn that they completed. "Well Done" everyone.

Ben Sharp from Buckinghamshire for completing a run in September, known as "Running Home for Alex" for his son Alex who has just completed his treatment for neuroblastoma. Ben has raised a fine sum of money from his event, which has been

generously matched by his employers, *BAA Communities Trust*. Also some local fund-raising by *Mrs Diane Goford*, and selling firewood.

Mr & Mrs S J Fisher to support the work of the Society.

Steven Middleton & colleagues from Royal Mail area WN1 1AA. Royal Mail encourages colleagues to volunteer and fundraise in their local community, and have very kindly matched the sum that Steven and his colleagues raised.

APM Metals Ltd from waste metals collected by Chris Ewell. Special thanks go to *Karen from Sainsburys in Sittingbourne* for all her help.

Kathryn & Jamie McDermott from "The Race Night" which was held at their local Cherrytree pub. They will soon be in training for taking part in The Great North Run again next year.

Elizabeth Paton from Dunkeld, on behalf of her friend Helen who is celebrating her 50th birthday this year, and has asked for donations to the Society in lieu of gifts, in memory of her beloved daughter Laura who she sadly lost to neuroblastoma when she was just a toddler.

Mary Abbott from London, from The Jamie Abbott Annual Golf Day.

Julia Stevenson from Crawley and her friend who held a Table Top & Craft Sale to raise money for the Society and for The Matthew Russo Foundation which supports local charities and children with special needs. This donation was, as always, in memory of Julia's dear son Ben.

Mrs Julie Lynch from Crawley, from the sale of her handmade jewellery, in memory of her beloved grandson Ben Stevenson.

Shaun Davies from Buckinghamshire who works for *Staples UK* which held a Charity Day throughout the whole company. Employees were each asked to nominate

a charity, Shaun chose to nominate the Society in memory of his nephew Jake Hall, and his charity was chosen to benefit.

Steve Williams Secretary of the Evening Star Lodge in Wirral, in memory of Katy Horton.

In 2010 *Mike Hall* from Surrey, completed a "Year of Running Dangerously" event, and raised a marvellous donation for the Society in memory of his nephew Jake Hall. Following up from this, Mike's employers *Cellular Asset Management Ltd* have generously matched the amount that Mike raised.

In addition to this Mike's wife *Suzi* works at *Birds Eye, IT Team*, and they held another of their Charity Cake Bakes to raise money for the Society. Mike and Suzi also ran a couple of Car Boot Sales to swell the funds even further, also in memory of Jake Hall.

Bill Sharp from Rickmansworth, from his "Grandpa Walks for Alex" event.

Mrs Mary Waterhouse from Somerset, from a donation, and sales of Society notelets.

The Douglas Martin Trust from Devon, in memory of Zak Hobbs.

Mrs Audrey Castleton from Croydon, in lieu of a gift for the 95th birthday of *Mrs Leonora Williams*, at her request. Also donations from *Sue & Barry Keegan & family, Mrs B Cameron, and G & L Mark, Mrs E A Blackwell, Mr D H Jeanes, Mr N Ford, Mr M B Ford, Mr S G Ford, Mr & Mrs J L Bruce, Mrs L M & Mr M Williams, & Fiona Avenalle, Mrs Dorothy Richards and Mrs Pat Conolly.*

Mrs Hazel Weston from Somerset to help all young sufferers from neuroblastoma like her friend Mary Waterhouse's grandson Luke.

Sue Citron from Surrey, who donated her Winter Fuel allowance to the Society, especially for her great nephew Thomas

Hudson, who is currently undergoing treatment at Leeds General Infirmary.

Donations received in respect of the late Mrs Evelyn Henderson.

Alice Roper from Kent, was diagnosed with neuroblastoma when she was 3 months old and is now a healthy 11 year old who loves swimming and horse riding. Alice recently held a cake sale, making and decorating all the cakes herself, to earn her fundraising badge from the Pony Club, and to raise money for the Society. Well Done Alice, and thank you for sharing your story with us.

Paulette & Mark Leppard from Qatar, for the support given by the Society to Ben Sneesby.

Mr John Garlick from Holmfirth, in memory of his beloved daughter Janet, who he sadly lost to neuroblastoma many years ago.

Mrs Margaret Farr, from North Shoebury, Essex, for a Christmas donation and some loose change, in memory of Tom Willson.

Liz Allen from Scotland, from the Dress Down Charity Group.

Mik Scarlet from London, from the pupils of his old school, Putteridge High School in Luton.

Paul Aust and staff at Thames Water Customer Services based in Kembrey Park Swindon, through their charity pantomime in January.

Gemma Woodhouse from a Carol Singing event.

Please send donations to:

The Accounting Officer
54 Forest Road, Richmond,
Surrey, TW9 3BZ

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	Vacant annualdraw@neuroblastoma.org.uk
Befriending	Mrs Caroline Nicolaidis— 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	Accounting Officer, 54 Forest Road, Richmond, Surrey, TW9 3BZ 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 Eileen Rowe—please contact via the Secretary
Pin Badges	Mrs Mary Waterhouse— pinbadges@neuroblastoma.org.uk
Stamp Appeal	Mr & Mrs C Wade, 13 Longacre Road, Cressing, Braintree, Essex, CM77 8HG
Website Co-ordination	Mrs Tori Oldridge— tori@bouncepr.co.uk

SOCIETY HELP LINE
FOR INFORMATION AND GENERAL ENQUIRIES
020 8940 4353



www.neuroblastoma.org.uk

