

Neuroblastoma Society –What We Do



The purpose of the Society is the relief of children suffering from neuroblastoma and to achieve this it raises funds for medical research into improving both the diagnosis and treatment of the disease. The Society also offers an opportunity for parents to give each other mutual help, support and comfort.

The Society aims to keep members updated on the latest treatments applicable to neuroblastoma and other medical advances relevant to the disease. The main way this is done is by supplying members with regular newsletters.

Our newsletter is produced up to four times a year and includes contact details for trustees and helpers, acknowledgments for donations, reports on latest research, personal reports about experiences of the disease and trustee business.

Current Research funded by the Society

Dr. S Lain, Dundee University – *JJ91* is a novel compound less harmful to the cell than current chemotherapy drugs. The aim of this study is to test its effectiveness on a pre-clinical model for neuroblastoma.

Dr. M Pule, London University – This study continues previous work on developing genetic engineered T-cells to treat relapsed neuroblastoma patients.

Prof. M White, Liverpool University – Neuroblastoma is effective in resisting current chemotherapy treatment designed to bring about cell death. This project will track the processes that keep neuroblastoma cells alive and study how old, new and combination chemotherapeutic agents affect these processes.

Prof. N Rahman, Inst. of Cancer Research -The aim is to identify and characterise neuroblastoma susceptibility genes in order to understand the underlying mechanisms causing the disease.

Dr. R Mairs, Glasgow University - This study continues earlier work that showed the effectiveness of combining *mIBG* and *topotecan*. This combination will be evaluated with three other cytotoxic drugs to see if effectiveness can be further improved.

Dr. A. Sala, London Institute of Child Health -This study tests the hypothesis that abnormal *B-MYB* expression may cause neuroblastoma. The function of *B-MYB* is essential for normal cell growth and development. Other studies have shown that it can interfere with *differentiation* of neuroblastoma cells and reduce sensitivity to chemotherapy drugs, as well as modifying the activity of tumour and growth suppressor proteins in the cell. A further grant was awarded in 2005 to extend this study for a further year.

Dr. C Redfearn, Newcastle University -This study explores whether novel agents like *fenretinide* (a synthetic version of vitamin A), used alone or in combination with conventional drugs will lead to substantial improvement in the prospects of children with high risk neuroblastoma. *Fenretinide* has been found to improve the effect of chemotherapy drugs. This study explores whether these effects are reproduced in a preclinical model and what the most effective treatment schedule would be.

Dr. G Flux, Royal Marsden NHS Trust/ICR - This study aims to develop methods needed to calculate the amount of energy deposited in tumour tissue when using *mIBG* therapy. This will provide the basis for tailoring treatment to individual patients, and will form the foundation for a European network for *mIBG* therapy. This may in turn generate further European funding and collaboration.

Professor S. Burchill, Leeds Institute of Molecular Medicine, St. James's University Hospital -*Minimal disease in children with high-risk neuroblastoma*. The study aims to apply a new technique (QRT-PCR) which is more sensitive than traditional methods, allowing detection of a single neuroblastoma cell, to bone marrow and tumour samples from children with high-risk disease. This may provide a method to monitor the response of children to therapy, allowing doctors to identify children who may benefit from increased therapy and those for whom additional therapy may be unnecessary.

Dr L. Chesler, Institute of Cancer Research, Royal Marsden Hospital -*Development of Mycn-targeted drugs for the treatment of high-risk neuroblastoma*. The study aims to test a second generation of drugs known as PI3-kinase inhibitors that target the Mycn protein without damaging other tissues and cells, which is a major factor affecting how well a child copes with and responds to treatment.

Dr D. Moss, University of Liverpool -*Using lessons from embryonic neural development to disarm cancer stem cells in neuroblastoma*. The study will test if introducing neuroblastoma cells into an early embryonic environment reprograms them toward benign behaviour, taking its cue from the way that embryonic stem cells and melanoma cells change their 'normal' behaviour when transplanted to a different environment. This would help determine ways to divert neuroblastoma cancer stem cells away from tumour formation and into benign and hence curable derivatives.

Dr Sala, University College of London Institute of Child Health -*Re-activating ApoJ/clusterin expression as a novel therapeutic approach for neuroblastoma*. This study takes aims to propose to understand the precise mechanism by which MYCN (a gene implicated in aggressive neuroblastoma) downregulates the ApoJ/clusterin gene, and whether reactivating ApoJ/clusterin inhibits neuroblastoma development. These so-called "epigenetic" drugs are already approved for use in adults so success with the project could pave the way to their use for children with aggressive neuroblastomas.

Dr N Bown, Northern Genetics Service, Institute for Human Genetics, Newcastle upon Tyne -*U.K. National Reference Centre for Neuroblastoma Biology*. This award is to enable the continuation for the next 3 years of an analysis service already used by hospitals for existing neuroblastoma cases. It is a centre of excellence for assessing the biology of neuroblastoma tumours using fluorescent in situ hybridisation (FISH) and multiplex ligation-dependent probe amplification (MLPA).



Ways we Fundraise

...pin badges...stamps...recycling...annual draw...monthly draw...Christmas cards...collecting boxes...fun s...marathons...triathlons...golf days...coast to coast walks...desert treks...Give as You Earn...legacies...concerts...lunches...birthday parties...bingo...football...fashion shows...

WHAT WILL YOU DO?



Society Contacts

Annual Draw : Mr Des Fordham, 22 Norwich Street, Cambridge, CB2 1NE

Christmas and other cards: Mrs Shirley Clark (see address on page 1)

Collecting boxes: Laurie Bradshaw, Orchard House, Bulmer, York, YO60 7BL; 01653 619766

Donations: Mrs Maureen Peters, 189 High Street, Great Wakering, Essex, SS3 0EA

Fundraising Packs: Lynne Christian (see address page 1)

Monthly Draw Club: Mrs Michelle Stephenson, 9 Reservoir Road, Erdington, Birmingham, B23 6DA

Society Pin badges:
LynnegardnerNSOC@aol.com
Tel: 0115 9211783



Stamp Appeal : Mr and Mrs Wade, 13 Longacre Road, Cressing, Braintree, Essex, CM77 8HG

Trustee contacts

Dennis Bignell, Beech Lodge, 22 Penrose Way, Four Marks, Alton, Hampshire, GU34 5BG; 01420 563826
secretary@neuroblastoma.org.uk (*Secretary*)

Shirley Clark, 54 Forest Road, Richmond, Surrey, TW9 3BZ, 0208948 2671 membership@neuroblastoma.org.uk (*Membership Secretary and Society Card Co-ordinator*)

Susanne Davies, 10 Brookland Road, Hagley, West Midlands, DY9 0JZ, 01562 886666 publicity@neuroblastoma.org.uk (*Press, Newsletter*)

Tracy Davies, Orchard Villa, Treadaway Road, Flackwell Heath, Bucks HP10 9NY 01628 532901
fundraising@neuroblastoma.org.uk (*fundraising*)

James Duberly, The Cottage, 25 Main Road, Stonely, St Neots, Cambs, PE19 5EH, 01480 860225
treasurer@neuroblastoma.org.uk (*Treasurer*)

Stuart Spokes, 68 Sundown Avenue, Dunstable, Bedfordshire LU5 4AL 01582 658884 marathon@neuroblastoma.org.uk (*sports*)

Stephen Smith, 2 Caesar Court, Moss Street, York, YO23 1DD, 01904 633744 chairman@neuroblastoma.org.uk (*Chairman*)

Medical Trustees (please contact via the Chairman)

Dr Penelope Brock, Great Ormond Street Hospital NHS Trust and Institute of Child health, London

Mr Keith Holmes, St George's Hospital NHS Trust, London

Justgiving has been a real fund-raising bonus for the Society. Each fundraiser can choose the charity and set up an individual page. They can then give friends, relatives and colleagues the web address and donations can be made by credit and debit card. If the giver is a tax payer they can opt for gift aid and the tax is reclaimed by justgiving and both that and the sponsorship are paid directly to the Charity's bank account.

Go to www.justgiving.com/nsoc/raisemoney