How You Can Help

- Donations are always welcome. Cheques payable to *The Neuroblastoma Society* can be sent to The Accounting Officer, 49 St Asaph Road, Dyserth, Rhyl, Denbighshire, LL18 6HG, or give online via JustGiving or MyDonate.
- Taxpayers can increase their giving through Gift Aid by providing their address and adding this declaration in a covering letter: *Please treat this gift as a Gift Aid donation and reclaim tax on it. I confirm that I pay tax at least equal to the tax on this donation.*
- Organise a fundraising event—contact fundraising@neuroblastoma.org.uk for advice.
- The Society has a few guaranteed places in the London Marathon and other prestigious races each year. Get more details from our Sports Trustee: sports@neuroblastoma.org.uk
- Other sponsored events are popular. We can provide sponsor forms and T-shirts.
- Save used postage stamps for our Stamp Appeal. Foreign and British commemorative stamps are best. Tear them from the envelope and send them to Mr & Mrs Wade, 13 Longacre Road, Cressing, Braintree, Essex, CM77 8HG.
- Find us on Facebook and follow us on Twitter @NeuroblastomaUK

The Society

- The Society was founded in October 1982 by a group of parents whose children were suffering from, or had died from, neuroblastoma.
- The Trust, establishing the Society as a registered national charity, came into effect on 20 May 1983.
- The Trust is overseen by lay Trustees who are parents or close family members of a neuroblastoma child. There are also Medical Trustees who are leading clinicians with extensive experience of treating the disease.
- The Society is run entirely by voluntary effort, keeping administration costs to a minimum.
- The Society's main objective is to raise funds for UK-based medical research into improving the treatment of neuroblastoma and eventually finding a cure.
- The Society also offers support through its befriending scheme and provides much needed information to parents and families affected by neuroblastoma.
- Around 90-95% of all money received is used to fund dedicated neuroblastoma research at specialist centres.
- Join us by contacting our Membership Secretary at membership@neuroblastoma.org.uk

The Neuroblastoma Society
fighting childhood cancer
Registered Charity No 326385

Find out more about this aggressive childhood cancer and please

HELP US FIND A CURE

Registered address:
The Neuroblastoma Society
2 Caesar Court
Moss Street
York
YO23 1DD

Information Line:
020 8940 4353

www.neuroblastoma.org.uk
secretary@neuroblastoma.org.uk

Facts About Neuroblastoma

- Neuroblastoma is a very aggressive childhood cancer responsible for 15% of all childhood cancer deaths. The cause of neuroblastoma is unknown in most cases.
- It is a solid tumour which arises in cells that run up the back of a child's abdomen and chest following the line of the spinal cord (neuro = nerve, blastoma = collection of tumour cells) and is most commonly found in the adrenal gland.
- About 100 children (two a week) develop neuroblastoma each year in the UK, the majority of whom are under four years old.
- Because the symptoms of the disease vary and are easily confused with simple childhood ailments, the majority of children are not diagnosed until the cancer is widespread.
- About half the children are diagnosed with 'high risk' disease, defined as the child being over 18 months of age at diagnosis and where the disease has spread through the body, or with too many copies of a gene called MYCN.
- Despite intensive courses of chemotherapy, and often initial success in arresting the disease, half of children with high risk disease will not survive.
- Those that do survive can have debilitating long-term side effects of the severe treatments.

Treatment

- Around half of children diagnosed with neuroblastoma have the most aggressive high risk disease and are treated with chemotherapy to shrink the primary tumour.
- Wherever possible this is then removed by surgery followed by high dose chemotherapy and stem cell rescue in the hope of eliminating all the remaining neuroblastoma cells. Children have to be in isolation for four to six weeks during this part of the treatment. Radiotherapy may also be given.
- Finally, when there are very low levels of disease remaining, children may receive differentiation therapy and immunotherapy which utilises the body's own immune system to fight the disease. We are hopeful that the new immunotherapy treatment will deliver a much improved long-term survival of at least 50% for children with high risk disease.

Progress

- Survival of UK children with neuroblastoma has improved over the past 25 years through funded research leading to effective clinical trials.
- Now 66% can expect to survive at least five years after diagnosis, compared with 21% twenty years ago. Sadly, around half of children with high risk disease remain incurable.

Research

- The Society has funded almost £3mn of specific neuroblastoma research in the past decade.
- The Society's independent Scientific Advisory Board vets applications for funding and advises Trustees on suitable projects to support.
- UK researchers work closely with neuroblastoma groups worldwide and regularly share knowledge, eg through the biennial Neuroblastoma Research Symposium that the Society runs.
- Current research aims to find new treatments and to improve the effectiveness of chemotherapy and radiotherapy as well as finding ways to ensure that all neuroblastoma cells are eliminated, informing clinical trials.

Clinical Trials

- Improvements in treatment of neuroblastoma come through clinical trials, where the effects and outcomes of particular aspects of treatment are measured consistently and reliably over time to see if they improve survival.
- Clinical trials may also involve the comparison of different treatments where it is not known whether one drug or procedure is more effective than another.
- UK treatment centres now take part in European-wide trials that are able to recruit a larger number of children and reach conclusions more quickly.