

NACCPO Member groups

Bone Cancer Research Trust

Description:

Devoted to promoting research into the causes and treatment of Primary Bone Cancer, and in particular of Osteosarcoma and Ewing's Sarcoma. The Trust provides information and in due course plans to offer support and counselling services for patients, former patients, families and friends.

Contact

E-mail: info@bonecancerresearch.org.uk

Website: www.bonecancerresearch.org.uk

Registered Charity No. 1113276

Bryan Gunn's Appeal

The Appeal was set up by the dove trust in April 1993 in memory of Francesca Gunn who died from Leukaemia in 1992. At the time Bryan was goalkeeper in Norwich City's premiership and UEFA cup team and was capped for Scotland.

With public sympathy and support from the whole of the sporting world and the people of Norfolk an Appeal was launched to support the relief of childhood leukaemia in three main ways:

- equipping local hospitals to be better able to deal with children suffering from the disease on both in-patient and out-patient bases.
- providing training for nurses and other staff involved in the care of children with leukaemia over and above that which is available from their employers.
- to support further research into the causes and cures of leukaemia.

Many projects have been funded to date including:

Establishing a laboratory for research into the causes and cures of childhood leukaemia at the University of East Anglia.

The funding of two PhD lectureships at the University and a senior research fellowship post.

The provision of specialist equipment for a new leukaemia and lymphoma diagnostic laboratory, and research at the Norfolk and Norwich Hospital.

Funding for nurses paediatric oncology courses; funding for a Paediatric Outreach Oncology Nurse for a three year period at the Norfolk & Norwich University Hospital.

Funding for a Paediatric Oncology Nurse for a three year period at James Paget Hospital.

Funding for Dr Beny Spira in Sao Paulo, Brazil who is currently investigating the effects of some Brazilian medicinal plants on leukaemia.

Setting up gaps:line to provide support for families and carers of children with leukaemia and cancer.

We hope that the support and help provided by the appeal benefits others like us who have to experience the trauma of coping with a child who has a life threatening illness.

CALM – Children’s Cancer and Leukaemia Movement

CALM is an independent local charity caring for the needs of families within the Swindon Health District, Wiltshire – as far as Marlborough, Hungerford, Calne, Devizes, Cirencester, Tetbury, Lambourn and Malmesbury who have children suffering from Cancer or Leukaemia.

Aims and objectives are:

- to improve the quality of life for the child sufferers
- to give support to the families during the often long and painful treatment and beyond.

Candlelighters – Leeds

Description:

Support group for families of children and adolescents with cancer being treated in the Paediatric Oncology and Haematology Unit, St. James University Hospital, Leeds.

Support groups for siblings, adolescents, teenagers, bereaved families and patients with brain tumours.

Contact:

CANDLELIGHTERS
Children’s Day Hospital
St. James’s University Hospital
Beckett Street
Leeds LS9 7TF

Website: www.candlelighters.org.uk

Sally Amos
(also NACCPO Secretary)
Tel: 0113 247 0372
Email: sally.amos@leedsth.nhs.uk

Pauline Jolley
Support Worker
Tel: 0113 247 0372

Registered Charity No. 1045077

CCUPA – Childhood Cancer Unit Parent’s Association

Description:

A support group for families of children with cancer being treated at the Royal Marsden Children's Unit.

Contact:

CCUPA – Childhood Cancer Unit Parent's Association,
Royal Marsden Hospital
Downes Road
Sutton
Surrey

Carey Smith
Tel: 07761 413672
Email: carey.smith@transvergence.com

CHECT – Childhood Eye Cancer Trust

Chief Executive: Libby Halford

Operations manager: Linden Smith

CHECT
The Royal London Hospital
Whitechapel Road
London
E1 1BB

Tel: 020 7377 5578

Email: info@chect.org.uk

Website: www.chect.org.uk

Further information on CHECT:

The Childhood Eye Cancer Trust has been a registered charity since 1987 and was formerly known as The Retinoblastoma Society.

Our aims are:

To provide information and support to individuals and families with children diagnosed with a rare form of eye cancer which affects the retina in small children.

To raise awareness of this disease amongst health professionals and members of the public, in order to achieve earlier diagnosis, thus preserving life and sight.

To raise funds for research into various aspects of retinoblastoma in order to enhance diagnosis, treatment and care.

CHICS - Children's Cancer Support Group

Description:

Support Group for families of children with cancer or leukaemia being treated at Alder Hey Hospital in Liverpool. Covers families from Merseyside, the Wirral and North Wales.

Aims and Functions of CHICS

The Children's Cancer Support Group, formed in 1986, provides support and information for parents of children with cancer by the following means:

MEETINGS: Regular meetings to inform members about the many aspects of childhood cancers and to enable members to gain confidence by sharing their experiences with each other.

SOCIAL FUNCTIONS: At which you can meet other families on an informal basis.

NEWSLETTER: A regular newsletter in which group activities are reported.

INFORMATION: A small library of books, leaflets and brochures, has been established for parents to gain more information about cancer treatments and cancer related national bodies.

FUND-RAISING: Fund raising events are held to finance the groups' activities and to enhance facilities at the hospital.

LINK-UPS: CHICS is a founding member of the National Alliance of Childhood Cancer Parents Organisations.

CARAVANS: CHICS also have 3 caravans, located near Blackpool and in North Wales, for respite use.

Contact:

CHICS – Children's Cancer Support Group

Alderhey Hospital

Liverpool CHICS Office

Tel: 0151 523 8886

Website: www.chics.org.uk

Eddie Hincks CHICS (Liverpool) Co-ordinator

22 Ayrshire Road,

Liverpool

L4 7XW

Tel: 0151 260 9331

Email: eddie.chics@blueyonder.co.uk

Erica Handley

Family Liaison Officer North Wales & West Cheshire Group

Email: ericadavidh@aol.com

COPARS (Childhood Cancer Organisation for Parents and Relatives Support)

Description:

The organisation was launched on 8th April 1994 after a number of parents, encouraged by staff at Addenbrookes Hospital, decided that a support group could offer a great deal to the families of children with cancer on Ward C2, both during and after treatment.

The committee is made up of volunteers who have themselves experienced childhood cancer in the past and can sympathise and understand the difficulties encountered by families with a very sick child. Two COPARS volunteers usually visit the parents' room once a week during the evening, to chat with parents, carers and relatives whom may wish to take a break from routines of hospital life. The ward staff kindly inform families of these visits and everyone is welcome.

The committee also organise 4 social events a year which include all the family.

Contact name and address:

Mrs Jane Levien

5 Hauxton Road

Cambridge

CB2 2LT

Telephone: 01223 570512

Email address: jlevien@identifydirect.com

Website: www.copars.org

Registered Charity Number: 1042081

Donnas Dream House – Provides free holidays in Blackpool throughout the year for terminally ill children and their families. With the magnificent playroom and the four themed apartments Donna's Dream House brings a sense of fun into children's lives.

These children would be those who are unable to take holidays in Florida, or will be recommended for placement by Hospice staff, The Kensington Foundation, Hospitals and many other sources.

There is also now a new teenage unit offering holidays for older patients.

Donna's Dream House
39/41 Chapel Street
Blackpool Central
FY1 5AW

Tel: 01253 752222

Fax: 01253 753450

Email: lencurtis@btconnect.com

Website: www.donnasdreamhouse.org

The Forget-Me-Not Children's Trust

Description:

A support group for bereaved parents from the Royal Marsden Children's Unit.

Contact name and address:

Jacquie Palmer

2 Forge Close,

Hayes

Kent

BR2 7LP

Tel: 020 846 21377

Email: jacquiepalmer4@hotmail.com

gaps:line

gaps:line is a telephone support line for parents and carers of children with cancer.

Staffed by a trained team of volunteer parents, all of whom have had a child with cancer, the line is open from 8pm to 10pm, seven days a week.

gaps:line is not a medical helpline, but provides a caring, listening ear and emotional support.

The line is also open to calls from concerned grandparents, relatives and friends.

Helpline: **0845 121 4277**

Contact:

BARBARA BRYANT (gaps:line Project Co-ordinator)

PO Box 92,

Dereham NR20 4WD

Tel: 0845 130 3686

Email: barbara@dovetrust.com

Website: www.gaps.uk.com

Katie's Trust

Description:

A support group for parents of children with cancer being treated at Newcastle General Hospital.

Contact name and address:

Martin Neal
32 Zetland Road
Redcar
TS10 3QD

Tel: 01642 293186

Email: katietrust@ntlworld.com

Website: www.katietrust.org

Leucan

Description:

A support group for families of children and young adults up to 25 years old with leukaemia or cancer living in the West Sussex area, from Shoreham to Chichester and inland.

Contact name and address:

Ian Camburn
Bay Tree House
Lyminster
Littlehampton
West Sussex

Tel: 01903-884955

Email: ian.camburn@btinternet.com

The Lisa Thaxter Trust

Description

The Lisa Thaxter Trust is a grant making trust providing relief to children with cancer and their families.

Contact:

Geoff and Gill Thaxter
1 Betjeman Close
Coulston
Surrey CR5 2LU

Tel: 01737 555411

Email: thaxter@litrust.freemove.co.uk

Website: www.lisathaxter.org

Registered charity number 1056017

The Neuroblastoma Society

Description:

The Society was formed in October 1982 by a group of parents whose children were suffering from or had died from Neuroblastoma, a very aggressive childhood cancer affecting children up to about the age of 14 years. The Trust Deed formally creating the charity was signed on 20 May 1983.

The sole 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 diagnosis and treatment of the disease.

The Society also offers an opportunity for parents to give each other mutual help, support and comfort.

We aim to keep members updated on the latest treatments applicable to Neuroblastoma and any other medical advances relevant to the disease. The main way this is done is by supplying members with regular Newsletter - something we do four times a year.

Contact:
Stephen Smith
9 The Archway
Little Hallfield Road
York YO31 7UH

Email: stephensmith@nsoc.co.uk

Website: www.nsoc.co.uk

PACT- Parents Association of Children with Tumours and Leukaemia

Description:

Support group for families of children with cancer and leukaemia being treated at Sheffield Children's Hospital.

Contact address:

BERYL WELBURN (PACT Co-ordinator)
PACT- Parents Association of Children with Tumours and Leukaemia,
Sheffield Children's Hospital,
Western Bank,
Sheffield S10 2TH

Tel: 0114 272 4570

Email: PACT@sch.nhs.uk

PASIC (Parents Association for Seriously Ill Children)

Description:

PASIC is a parent support group for families of children diagnosed with cancer and receiving at least part of their treatment at Queen's Medical Centre or Nottingham City Hospital.

The PASIC Coordinator makes visits to the wards and clinics to meet with parents. PASIC offers financial, practical and emotional support. There is a 24 hour answerphone and a quarterly newsletter.

Social events include parties and outings that bring the families together in a relaxed atmosphere and enable them to make friends with other families who are experiencing similar situations.

Contact name and address:
PASIC - BEA BRUNTON (PASIC Coordinator)
Parents Association for Seriously Ill Children
(c/o Ward E38)
Queen's Medical Centre
Nottingham NG7 2UH

Tel: 01623 747629

Email: mail@pasic.org.uk
Website: www.pasic.org.uk

Registered Charity Number: 506778

Poole and District Children's Cancer Fund

Description:

A support group for parents of children with cancer being treated at Poole General Hospital, Poole, Dorset.

ROHBTS – Royal Orthopaedic Bone Tumour Society

Description:

A support group for families with a child with bone cancer.

Contact name and address:

Jenny Richardson
The Brick House
Lower Wood Road
Ludlow
Shropshire SY8 2JQ

Tel: 01584-856209

Liz Gibbs
5 Coppice View Road,
Sutton Coldfield B73 6UE

Tel: 0121 624 4734

Email: liz.gibbs@hotmail.com

The Samantha Jones Trust

The friends and family of sixteen-year-old Samantha, who lost her battle with leukaemia in 2002, set up The Samantha Jones Trust in September 2004.

Our charitable aims are:

The relief of sickness and distress of children suffering from Leukaemia and their families by the promotion of research into the causes and prevention of Leukaemia and the provision of support, financial and material assistance and such other services as the trustees shall from time to time in their absolute discretion determine.

Contact - Keith Jones

Tel/fax - 01457 829479

Email - enquiry@thesamanthajonestrust.com

Website - www.thesamanthajonestrust.co.uk

SCY - Support for Cancer in Youngsters

Description: A support group for parents of children with cancer being treated at Ipswich Hospital.

Contact name and address:

Mary Allen
The Hedges
Marlesford
Woodbridge
Suffolk
IP13 0AE

Tel: 01728-746511

Email: mooallen@hotmail.com

SPOCC - Society of Parents of Children with Cancer

Description:

Support group for families and children with cancer being treated at the Birmingham Children's Hospital.

Contact name and address:

Su Coleman
SPoCC Link Worker
Oncology Clinic
Birmingham Children's Hospital
Steelhouse Lane
Birmingham B4 6EN

Tel: 024-7660-3577

Email: spocclink@tiscali.co.uk

TCCL – Tayside Children with Cancer and Leukaemia

Description: Support group for families of children with cancer in the Tayside area.

Contact:

Chairperson Vicki Low
11 Bower Mill Lane
Dundee DD3 9UE

Tel: 01382 827201

Email: andrew-low@supanet.com

Website: www.tccl.org.uk

ASSOCIATE MEMBER GROUPS

Barretstown

Description:

Barretstown is a specially-designed camp that provides Therapeutic Recreation programmes for children with serious illnesses, and their families. Excellent, unobtrusive medical supervision helps children with cancer and other diseases forget illness, learn to have fun and rebuild their confidence and self-esteem. Our programmes take place at a fairytale castle in the beautiful foothills of Ireland's Wicklow Mountains.

Contact name and address:

The Barretstown Camp Fund Ltd,
Barretstown Castle,
Ballymore Eustace,
Co Kildare,
Ireland

Tel: 00353 45 864 115

Fax: 00353 45 864 197

Email: info@barretstown.org

Website: www.barretstown.org

Camp Quality UK

Description:

Camp Quality is a non-profit making charity that brings hope, opportunity and new challenges for children with cancer and leukaemia through fun, inspiring and relevant holiday-based activities.

Contact name and address:

Camp Quality UK
PO Box 217
Sidcup
DA15 0BL
Tel: 07983 563747

Email: delyth.thomas@campquality.org.uk or

steve.cox@campquality.org.uk

Website: www.campquality.org.uk

CLIC SARGENT

Offers children with cancer and their families all round care and support.

Contact name and address:

CLIC SARGENT
London Office Griffin House
161 Hammersmith Road
London W6 8SG

Tel: 020 8752 2800

Website: www.clicsargent.org.uk

- [Geoff Thaxter](#)
- [Susan George](#)
- Emily Bird Emily.Bird@clicsargent.org.uk
- [Pilar Gonzales-Doupe](#)

Child Cancer Helpline: 0800 197 0068

The Over the Wall Gang Camp

Description:

Over The Wall is a very special place for children affected by cancer and other serious illnesses. It is the only residential Camp in the UK modelled after Paul Newman's renowned The Hole in The Wall Gang Camp. OTW gives children one glorious week of having fun, making friends, meeting new challenges and rebuilding confidence. More importantly it is a place where they can be just kids, not kids who are sick.

Contact:

The Over The Wall Gang Camp
Alderney House
58 Normandy St
Alton
Hants GU34 1DE

Tel: 01420- 82086

Email: info@overthewallgangcamp.org.uk

Website: www.overthewallgangcamp.org.uk

David Howarth email: david@overthewallgangcamp.org.uk

Teenage Cancer Trust

The charity focuses on the needs of teenagers and young adults with cancer, leukaemia, Hodgkin's and related diseases by providing specialist teenage units in NHS hospitals.

Contact name and address:

Simon Davies – Chief Executive

Email: simon@teenagecancertrust.org

38 Warren St

London W1T 6AE

Tel: 020 7387 1000

Email: tct@teenagecancertrust.org

Website: www.teenagecancertrust.org

