

News from the Forget me Not Children's Trust...

It is that time of year again as we run up to Christmas to update you on what has been happening in the FMNCT and to look forward to the Memorial Service and to getting through what is a difficult time of year for us all. Once again, this Newsletter has been put together with a great deal of help from Maureen and the CLIC Sargent team at the Marsden, to whom we are all very grateful for the support they give to all the families of children diagnosed with cancer.

The Christmas Service is again being held in the Out Patient area at the Marsden, Sutton. We have found that this works well for the numbers who come, and at the same time does not involve going through the hospital if it brings back unhappy memories. We look forward to welcoming you there and to the opportunity to mix and talk with other families who share the common burden of losing a child to cancer.

We have not organized a summer event this year, but are very happy to do so if you as the members, want it. Please let us have any ideas you may have for such an event.

The FMNCT continues to be involved in representing children and young adult cancer patients and their families in a number of wider areas. These include the review of Children and Young Adults Cancer Services, as well as clinical research activities. If you would like to help with these and other future activities, please contact us, as your experience is invaluable and can be used to make things better for future children.

It only remains for us to wish you all the best Christmas possible, and the hope of seeing you at one of the FMNCT activities. If anyone wants to get involved in the running of the FMNCT, please also contact us, as new leaders contribute enormously to making the FMNCT relevant to us and our families.

Richard and Jacquie Palmer, Chair & Secretary, FMNCT

Geoff Thaxter

During the summer we learned of the sad death of Geoff Thaxter, who has been a FMNCT member for many years and who often read at the Christmas Service. He was also the founder, with Gill, of the Lisa Thaxter Trust, who have generously supported the FMNCT financially over the years. Lisa was a patient at the Marsden Children's Unit.

CHRISTMAS SERVICE Saturday December 13th at 5pm Royal Marsden Hospital, Sutton

This year's service of remembrance will be held on Saturday December 13th in the **Adult Out-Patient area** of the hospital located just by the main entrance. The service will start at 5pm and be followed by refreshments in the main hospital dining room to which everyone is invited. Families attending may like to bring a present in memory of their child who has died. These presents will be collected during the course of the service and distributed to children with cancer over the Christmas period. On behalf of the FMNCT and the hospital we very much look forward to meeting families who will be attending for the first time this year and also welcoming back some of our 'old friends' for whom this has become an important part of their Christmas ritual.

If you are not able to come - but would like your child's name read out during the course of the service - please ring the CLIC Sargent Team on 020 8661 3880 to request this.

Geoff contributed to improving children's cancer both in the UK and around the world and will be sadly missed. We extend our condolences to Gill and their daughter Becky, at what will be a doubly sad time this Christmas.

Richard Palmer

Holidays for bereaved families

This year we are pleased to include in the Newsletter a comprehensive list of organisations who are happy to offer holidays to bereaved families as well as children on active treatment. We are very grateful to Claire Marshall who contacted all these organisations earlier this year on our behalf to produce this list - many thanks for all your hard work on this project Claire.

Barretstown Castle, Ireland

www.barretstown.org - a bereavement programme in a supportive environment

Children with Cancer Fund, East Sussex

www.childrenwithcancerfund.co.uk - luxury caravan on Coghurst Hall Holiday Village

Christian Lewis Trust

www.christianlewisrust.org - 4 luxury caravans in South, North and Mid Wales and Blackpool

CLIC Sargent

www.clicsargent.org.uk

- 4 luxury caravans in Devon, West Sussex, Lancashire and Yorkshire
- Malcolm Sargent House (Prestwick, Ayrshire) a bereavement programme in a supportive environment

Colleens Tenderheart Charity

- contact CLIC Sargent at RMH 020 8661 3880
- luxury caravan at Crowhurst Park Holiday Centre, East Sussex

Joshua Foundation

www.thejoshuafoundation.co.uk

- 3 holiday homes in Pembrokeshire - only available to bereaved families outside of school holiday periods

Lennox Children's Cancer Fund

www.lennoxccf.org.uk

- holiday homes in Hampshire, North Yorkshire, Northumberland and Cumbria

Miracles

- contact CLIC Sargent at RMH - 020 8661 3880
- small charity based in West Sussex - may be able to help with finances towards a holiday which families book themselves

Oakley Waterman Holidays

contact Lorraine Waterman 02392 710367
- 2 luxury caravans in Devon and West Sussex (same as CLIC Sargent sites)

The Oliver Curd Trust

www.theolivercurdtrust.co.uk

- luxury caravan in Crowhurst Park, East Sussex

REACT

- www.reactcharity.org
- holiday homes in Hastings, Isle of Wight, Skegness, Blackpool and Scotland

The Sand Rose Project

www.sandrose.org.uk

- holiday cottage in Cornwall

Thomas Ball Children's Cancer Fund

www.thomasball.org.uk
- 2 bed holiday chalet and 3 bed holiday lodge in Hampshire

If you would like more information, copies of the Newsletter, donations to the FMNCT and photographs/text for the Remembrance Book in the Chapel please contact -

The Forget Me Not Children's Trust
c/o CLIC Sargent Team
Royal Marsden Hospital
Downs Road
Sutton, Surrey SM2 5PT
Tel: 020 8661 3880
Or email Marion the Team PA on:
marion.rose@rmh.nhs.uk

Ward news...

New unit - The Trust will launch its fundraising campaign for the new unit at the start of 2009 - the aim is to raise 15million to extend and improve facilities for children and teenagers being treated at the hospital. It is anticipated that building work will start in the spring of 2009 subject to planning permission being granted. If you would like to know more about the campaign and how you can help contact Appeals on 020 8661 3391.

Farewell to.... Sadly the CLIC Sargent Team has lost two valued members of staff this year. Eileen Barr left at the end of August and Carolyn Turner left at the end of October to take up a post at Chase Children's Hospice. During her time at the Trust Carolyn had worked very closely with The Forget Me Not Children's Trust and played a key role in developing and running services for bereaved families.

Clare Daly left the Paediatric Oncology Outreach Nursing (POON) Team in March to take up a post at Great Ormond Street Hospital.

Joan Woodruff, Co-ordinator for Hospital Education at the Marsden retired at the end of the summer term. Joan, as many of you will know was the instigator of the annual ward pantomime which was enjoyed by families and staff alike. Alas there will be no pantomime this year!

All of these staff will be greatly missed by families and colleagues alike for their contribution to patient care. We wish them all well for the future.

New posts... Louise Soanes - Senior Sister (Paediatrics) has been appointed Nurse Consultant for young People - she will therefore play a key role in the development of services for teenagers and young adults in the Trust.

The Children/Young People Outreach and Symptom Care Team (formerly POONs team) has 2 new nurses who have joined this year - Lucy Coombes, who some of you may know from the ward, and Charlotte Bradbourne. The team have also been pleased to welcome Dr AK Anderson a Consultant in Paediatric Palliative Care whose post is funded by CLIC Sargent.

Bette Petersen Broyd has been appointed Co-ordinator for Hospital Education at the Marsden hospital school following Joan Woodruff's retirement.

Welcome also to Johanna Rowe, CLIC

Sargent Social Worker, who joined the Team in October 2008.

On behalf of the FMNCT we wish them all well in their new roles

Parent to Parent Befriending Service

The parent to parent befriending service continues to offer a confidential service to all parents whose child has died. Over the past year several families have made use of this service and have found the experience of meeting with another bereaved parent or parents both helpful and of comfort. The opportunity to talk to another bereaved parent who has a good idea of what and how you may be feeling, without having to explain, has proved to be reassuring to bereaved parents and helps confirm that their feelings are not unique.

The befrienders themselves are bereaved parents of children or young people who were treated at the Royal Marsden Hospital and who are at least five years post bereavement. All volunteers receive training and regular supervision by the CLIC Sargent Team at the Royal Marsden Hospital.

If you would like to see or hear from a befriender please contact the CLIC Sargent Social Work Team at the Royal Marsden Hospital on 020 8661 3880.

Bereaved Grandparents Day

In September Julie Shelton and Carolyn Turner from the CLIC Sargent Team at the Marsden organised a day for bereaved grandparents to come together. This was in response to a growing realisation that whilst the death of a child is so very difficult and upsetting for all members of the immediate as well as the extended family there were some very specific issues that grandparents could benefit from sharing with others in a similar position.

The grandparents who attended were generously able to share their story with others and offer each other some support, sympathy and most of all a true understanding and recognition of the feelings and worries they were going through. There was an acknowledgement that all of them would like to protect their own children from the pain they were experiencing as parents themselves. Their personal experiences, about what was difficult or useful, in relation to their loss, was enlightening to others as well as for us as workers within this area. The

grandparents said that they found it helpful to talk directly with other grandparents as there were so many similarities in the range of emotions they were going through. Support and understanding of others, who had had a grandchild die through cancer, whilst painful, also gave some comfort and encouragement to the grandparents who had attended the day.

We would like to thank all the grandparents who attended and also their children for giving them the encouragement to attend.

This poem was written by Ben Chandler when he was 10 years old. Sadly Ben died on the 29th September 2008 aged 20 and his parents very kindly gave permission for us to print his poem in the FMNCT Newsletter - thank you to the Chandler family.

I shall give you,
Ben Chandler

I shall give you a wizard's magic
For conjuring up spells,
I shall give you love in times that
are tragic.
I shall give you the gift of
hearing,
So you can hear me warning you.
I shall give you the gift of peace,
To carry round my message.
I shall listen to your every move,
So you are safe in life.
I shall lower you the softest
cradle,
To lie in when you are at the end
of your quest.
I shall give you the gift of love,
To love and not to hate.

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