

Chairman's letter

Once again that difficult time of Christmas is coming round again for us all. On behalf of the FMNCT committee, I would like to wish you all the best for Christmas and the hope that it will be as good as possible for you.

The FMNCT, together with Maureen, Marion and the CLIC Sargent Team, has continued to provide support to our member families through the Befriending Service, Group meetings, the Christmas Service and the Memory Books in the Chapel. We are also producing the Memory Corner Calendar (see below) as a first time 'try-out' this year.

The FMNCT continues to be part of the National Alliance of Childhood Cancer Parent organizations, providing input into a number of national initiatives, such as children's cancer services, neurosurgical services review and the CCLG, to name but a few. Although we no longer have our children, we have a valuable body of experience that can be used to improve the cancer journey for children and young people with cancer and their families in the future.

We would like to hear from you if you have any other ideas for support activities and especially if you would like to help the Committee in any way. Finally, the FMNCT is looking for a new Treasurer, as Tina Clay is stepping down after many years as Treasurer. We are all very grateful to Tina for her professional running of our finances for such a long time. With every best wish,

Richard Palmer
Chairman FMNCT

Memory Corner Calendar

In the past, we have produced a booklet at Christmas of the birthdays and anniversary dates of our children from the Memory Corner list that is in the cabinet that contains the memory books in the Royal Marsden Chapel. This list is made up of names of children that have been sent in by parents for the Memory Books. This year, we have decided to try producing this in a more professional, colourful and exciting format, as a calendar (flyer attached). Each month has the names and the birthdays and anniversaries that occur in that month, set in a colourful design. Copies of the calendar are available for a donation of £5.00 from the CLIC Sargent Team or from Richard Palmer at the address below, with proceeds going to cover production

CHRISTMAS SERVICE

Saturday December 12th at 5pm
Royal Marsden Hospital, Sutton

This year's **service of remembrance** will be held on Saturday December 12th in the **Adult Out-Patient area** of the hospital located just by the main entrance. This service coincides with the International Day for remembering children who have died. The service will start at 5pm and be followed by refreshments in the main hospital dining room to which everyone is invited. If you do not want to attend the service but would like to meet up with other families and staff you are welcome to join us for refreshments in the Dining Room at approximately 5.30pm. 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. The Forget Me Not Children's Trust looks forward to welcoming all families who wish to attend.

During the course of the service we traditionally read out the names of the children and young people whose families are in attendance. If however you are not able to come but would like your child's name read out during the service please ring the CLIC Sargent team on **020 8661 3880** to request this before 5pm on 11th December.

costs and to the Forget Me Not Children's Trust. Those of you who have pre-ordered copies will be able to collect them at the Christmas Service, or will have them sent to you before Christmas. If this proves to be a popular format for the Memory Corner, then we will look to produce it again in the future, and anyone whose child's name is not on it this year will have the opportunity to have their child's name included for next year.

We are very grateful to one of our members, Stuart Lynch, for designing the calendar for us.

Holiday updates

CLIC Sargent holidays for bereaved families:

As in previous years the charity will dedicate certain weeks at its Prestwick

holiday home in Ayreshire, Scotland for the exclusive use of families who have suffered bereavement. The planned dates for 2010 are:

Sat 27th March - Sat 3rd April
Sat 31st July - Sat 7th August
Sat 4th - Sat 11th September
Sat 4th - Sat 11th December

To book for any of these dates please contact the holiday administrator on **01292 671233** or email: malcolmsargenthouse@clicsargent.org.uk

For the first time this year the holiday home decided to offer a break to parents who had lost an only child. At the time of writing we have no feedback about this - but if it is well evaluated by those attending it may be repeated in future years.

For all other holiday information please see our website - www.forgetmenottrust.org.uk as last years newsletter included a comprehensive list of holiday providers.

Radio Marsden

For those who listened in to Radio Marsden when their child was an in-patient you may be interested to know that it is celebrating an important anniversary this year. Radio Marsden was founded in November 1969 and, to commemorate the fortieth anniversary of this achievement, they will be broadcasting on 87.7FM and online at radiomarsden.co.uk from 2nd - 29th November 2009 to Sutton and all surrounding areas. With a focus on celebrating the work and achievements of both the station and the two Royal Marsden hospitals (in Sutton and Chelsea) which the station serves, they will be broadcasting a mixture of music and magazine-style programmes, 24 hours a day, 7 days a week.

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 main news is that work is underway for the new unit and the builders are on target for the first phase to be completed by July 2010 when we will move in to the new unit and work can begin on revamping the current ward and day care facilities. The unit is being built on the back of the existing ward and the workmen have very kindly left some peep holes at different heights so that children and adults alike can spy on the progress. Anyone wishing to help with fundraising please contact the appeals team at RMH on 020 8661 3391 who will be very happy to hear from you -alternatively see Denise and Phil's article on "it's a wrap"!

Farewell to.... Sandra Earle and Vicky Ivie, Play Specialists; Kate Pye, Matron for Children's Services; Sam Peacock, Psychologist, has gone on maternity leave pending the birth of her third child.

Welcome back to... Tanya Turner is back from her maternity leave following the birth of her second child.

New posts on the ward - Clinical Nurse Specialist for Children and Young People with Brain and Spinal Tumours. Jo Stone/Luci Ellison both staff nurses within the unit were appointed as a job share and commence their new role in December 2009. This is viewed as an important development for families in provision of an improved service across the RMH, Kings College Hospital and the Atkinson Morley Unit (St Georges Hospital site).

Other new posts...

Some of you may be interested to hear that the developing Teenage and Young Adult Team have appointed a new member of staff John Carroll who is a TCT funded Youth Support Co-ordinator. John is meeting up with all teenage and young adult patients to help them cope during their in-patient stays and make sure they have appropriate activities to keep them occupied. John is also trying to help young people stay in touch outside of hospital and is keeping them posted about a variety of free events on offer.

Children and Young People's Outreach & Symptom Care Specialist Team:

Maggie Breen - Team leader - Macmillan Clinical Nurse Specialist; Charlotte Bradbourne - Specialist Sister; Lucy Coombes - Specialist Sister; Dr A K Anderson - Consultant Paediatrician in Paediatric Palliative Care

The team is evolving with the appointment of two specialist sisters and Dr Anderson during 2008. The nursing team has work experience in acute and community oncology care, health visiting and community children's nursing and children's hospice care. Dr Anderson has a joint appointment with the RMH and one of the children hospices that sit within the referral area for the RMH.

The team has been motivated over the last 12 months working together and seeking ways to improve our tertiary level specialist service to families and health and social care professionals across the South Thames. We have a planned consultation meeting with our colleagues across local shared care and community/hospice services to share and discuss our service development plans for 2010. It is planned for the future that families will be involved in sharing their experience to enhance further improvements to the overall service.

Parent to Parent Befriending Service

Parent to parent support is offered to parents following the death of their child. This provides an opportunity for parents to talk to another bereaved parent whose own child had previously been treated at the Marsden.

At a recent meeting with the parent Befrienders it was recognised that often the need for some discussion; conversation support etc may be required not just following the death but sometimes several years later. Some Befrienders felt that their need to talk about their experience came 3-5 years following the death of their child.

If you would like to have the opportunity to talk to another parent or couple please don't hesitate to contact the CLIC Sargent team at the Marsden who will then be able to put you in touch with our support parents.

Julie Shelton, CLIC Sargent Social Worker

A coping strategy - also great fun

When Alexander died we felt much the same as any other parents at the loss of a child. How to cope, how to make sense of what had happened, how we could do something positive to help others and busy ourselves at the same time. Thankfully we were introduced to the Lisa Thaxter Trust and in particular their gift wrapping service which was, at that time, beginning to be a very successful fundraiser for their charity.

A chat with Gill and Geoff Thaxter decided

us both that we would have a go. We thought that we were reasonably OK at wrapping but quite how we should cope with performing in front of other people, in Croydon's Whitgift Centre, was a bit of a concern. But it proved to be enormous fun and very satisfying. We could take our minds off the immediate loss of Alexander and give some time to helping others in the run up to Christmas.

The wrapping service is known as It's A Wrap and has now been running for 13 years. During this time it has raised more than £500,000 and has helped to fund a variety of projects helping children and adolescents with cancer. Although the Lisa Thaxter Trust has now closed the wrapping service continues with stands in Croydon, Crawley and Epsom shopping centres. Every day throughout December a band of like minded volunteers will wrap customers' presents, which they will have brought to us, in a choice of paper or box, decorate it with ribbons and bows and finished off with a gift card. This is in exchange for a suggested donation of around £2.50. Last year we wrapped approximately 10,000 parcels varying in size from an engagement ring to a bicycle. We'll try anything. Not all presents are Christmas presents and we have papers to suit most occasions for adults and children in a variety of patterns and colours.

Many customers come back year after year, some come simply because they don't like wrapping presents themselves but many come because they have a "cancer connection". Some need to talk and we find ourselves lending an ear and sometimes a tissue - this part of the "job" is as rewarding as any. When you have experienced the loss of a child you find yourself well placed to at least empathise with others. Several of our wrappers are also bereaved parents.

If you think that wrapping presents may help you over a difficult time and you want to join a friendly group of people having fun please contact Denise on 01883 342920 or e-mail at denisekclarke@hotmail.com for more information.

This year all monies raised will be donated to the Royal Marsden Cancer Campaign for the much needed new Children's and Teenage Cancer Centre.

Phil Clarke

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