

carers at kids

the children's hospital at Westmead

Newsletter April 2010

Families Online

A new advisory panel has started online for families with a child who has been cared for by The Children's Hospital at Westmead. It is called Families Online and becoming a member of the group will allow you to give feedback on projects being undertaken at the Hospital that will affect you and other families.

Would you like to help make The Children's Hospital at Westmead an even better place for children and families?

Do you have regular internet access and an email address?

If you answered "YES" to these questions, we would like you to join our Families Online email advisory panel.

What is Families Online?

Families Online is a group of parents and carers who provide the Hospital with feedback on any projects that will affect families. This could include proposed changes to parts of the Hospital, new services or communication strategies.

How does it work?

We'll email you a questionnaire or ask you to take an online survey, and you tell us what you think! We promise not to send out more than one or two emails per month. Your email address and details will be kept strictly confidential within the Service Improvement Unit – other Hospital staff and members of Families Online will not be able to view your details. It's up to you which surveys or questionnaires you want to respond to. Participation is always voluntary.

Who can join?

We're looking for people who come from all different backgrounds, who live all around NSW and ACT and who have been treated by all different areas of the Hospital. We want as many families as possible who can tell us how The Children's Hospital at Westmead can be even better.

Are you interested?

For more information or to register, go to www.chw.edu.au/parents/families_online.

Our Consumer Participation Coordinator, Joyce Murphy, will phone you to confirm your details and might ask a few extra questions to learn more about you and your child.

Note: The Carers Support Program will never pass your contact details on to third parties. Families Online is completely separate to your subscription to Carers at Kids.

Christmas hampers

If you were around the Hospital at Christmas you may have noticed the Parent and Carer Resource Centre full of beautiful Christmas hampers. Every year, the Carer Support Program, in conjunction with the Social Work Department, organises Christmas Hampers for needy families of patients in the Hospital. The hampers are donated by the departments of The Children's Hospital at Westmead. Each department that wants to participate is given specific family information so they can create a hamper that will meet the family's needs. The generosity of the contributing departments over the last few years is overwhelming and the enjoyment that the departments receive is evident from the amazing hampers that are produced.

Everyone who comes into the Parent and Carer Resource Centre over Christmas comments on how wonderful the hampers look and how much effort each department puts into making Christmas more special for our families.

In 2009, we had 46 Departments contribute 55 hampers for needy families, 11 more than the previous year. All of the feedback from the families who received a hamper has been extremely positive. Many recipients have been close to tears and all have been really grateful for their special gifts and the difference it made to their Christmas.



Starting school DVD

The NSW Government and Lady Gowrie Child Care Centre have joined forces to produce a DVD resource to help families who have a child with a disability starting school.

Some strategies include:

- You need to start planning early - one or two years before your child is due to start school. Selecting a school involves exploring choices. It is important for you to gather the information you need to assist you to make the best decision for your child.
- Before you start your search for a school it's a good idea to choose an advocate – someone to support you, as you support your child. This could be a friend, relative, or someone from a support or advocacy service. Choosing a school can be very emotional time for a family and having a third party to support you can be useful.
- Once you have chosen a school, you can begin working with that school in preparation for the school year. There can often be a need for the school to plan ahead to access any funding available to support your child. It is important to allow adequate time for this process to take place.

The DVD features the stories of six families as they prepared for their child with a disability to go to school for the first time.

Minister for Disability Services, Paul Lynch, said, "This resource reinforces important messages that encourage parents to talk with a range of people when making decisions about choice of educational settings for their child."

The resource was produced by the Lady Gowrie Child Centre, with funding from the NSW Government.

The DVD highlights the importance of parents and schools working together to identify the levels of support needed for each child. Importantly, it sets out the challenges they are likely to face and provides practical guidance for parents.

The information kit is produced in Arabic, Cantonese, Dari, Dinka, English, Korean, Mandarin and Vietnamese.

If carers are interested in obtaining a free copy of the DVD please call the Early Childhood Intervention Info line on **1300 65 68 65**.

Spotlight on volunteers

Our Parent and Carer Resource Centre wouldn't be able to run without our wonderful volunteers. We thought you may like to get to know them a little better, so we are interviewing one volunteer for each newsletter.

Our volunteer for this newsletter is one of our Wednesday ladies – Lorraine

Tell us a bit about yourself?

I am a very ordinary person and much involved with my family. I have three children and eight grandchildren. My husband and I will celebrate our 40th wedding anniversary this year (hopefully in Paris).

How long have you volunteered at The Children's Hospital at Westmead?

I have been volunteering for 15 months

Why is volunteering important to you?

Because it's about giving without the expectation of receiving anything back.

What do you like about volunteering?

I enjoy meeting people and hopefully I make a difference in a small way, by chatting and listening to parents' and carers' concerns and problems and by supplying useful information.

What did you do with yourself before volunteering?

Before becoming a volunteer I was a retired teacher, so volunteering has filled a gap in my life.



Lorraine, one of our wonderful volunteers.

Where were you born?

I was born in Liverpool and I have spent my married life in Greystanes.

What's your favourite food?

My favourite food is seafood but I like the occasional glass of wine.

What do you do for relaxation?

My hobbies include gardening, reading, patchwork, watching movies, travel and spending time with my grandchildren.

If you could invite any 4 people to dinner who would you invite?

If I could have a meal with four people I would chose my husband and two congenial friends for a relaxed meal.

Did you know?

- Beards are the fastest growing hair. If the average man never trimmed his beard, it could grow to 30 feet over the course of his lifetime!
- The human body makes one to three pints of saliva every 24 hours.
- It takes approximately 200,000 frowns to create one permanent brow line.
- In one day, a human sheds ten billion skin flakes. This amounts to approximately two kilograms in a year
- Your body uses 300 muscles to balance itself when you are standing still.

We want to hear from you!

We would like to be able to share your stories, experience and knowledge. If you have something to say, we are listening.

Give us a call on **9845 3590**, email kellyb1@chw.edu.au or speak to a volunteer in the Parent and Carer Resource Centre (they will take your details and we will get back to you).

If you are an organisation and you would like to advertise through us and let people know about your service for parents or carers, please contact Kelly on **9845 3590** or kellyb1@chw.edu.au



The Parent and Carer Resource Centre – It's your place!

If you need to take "time out" or if you want to locate information about a range of services, the Parent and Carer Resource Centre is the perfect place for you! We are located on level two of The Children's Hospital at Westmead opposite Kid's Health. Phone **02 9845 0580**.



Available at the centre:

- Carer service directories
- Daily papers
- Microwave
- Computer and internet access
- Free tea and coffee
- Access to Driver Reviver Room
- Free book exchange
- Regular activities and events for parents and carers
- Local information

If you would like to unsubscribe to this newsletter please email Kelly on

Kellyb1@chw.edu.au

the **children's** hospital at Westmead

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Locked Bag 4001 Westmead NSW 2145 Sydney Australia
Tel 02 9845 0000
Visit our website: www.chw.edu.au

Calendar

If you have courses or activities you would like added to our newsletter please don't hesitate to phone us on 9845 3590 or email Kelly Bowler kellyb1@chw.edu.au

Aspect Autism Spectrum Australia	
Aspect Recipe for Success	June 28th, 29th & 30th Cronulla
For more information call 02 8977 8300 or visit www.autismspectrum.org.au	

Northern Sydney Central Coast Area Health	
Northern Sydney Central Coast Area Health has lots of events and courses. Follow the link below then select Carer's Event Diary to find out more about the events and other information regarding carers.	
For more information check the website http://internet-apps.nscchahs.health.nsw.gov.au/eventdiary or call 8877 5349	

Family care workshops	
For more information contact Tracy Hadden on 9975 8410 or thadden@tscnsw.org.au or to view Workshop Schedule www.familycare.org.au	7, 20, 27 – April – St Marys 5, 12 – May – Campbelltown

Learning Links	
Including children with Autism Spectrum Disorders in the classroom – practices and priorities	April 19 – Peakhurst
Makaton – basic	20 April, 1, 8 June – Peakhurst 27 April, 31 May, 7 June – Narellan
Total Communication	May 5 – Frenchs Forest 21 April – Narellan
Communication matters	22 April – Peakhurst
Stress management for children with high functioning Autism or Aspergers Syndrome	28 April – Maroubra 2 June – Peakhurst

Behaviour as communication; a functional approach – behaviour management for children with disabilities	5, 12 May – Peakhurst
Practical strategies for helping young children with Developmental Verbal Dyspraxia	6 May – Peakhurst 28 June – Maroubra
Social skills & emotional management for children with high functioning Autism or Aspergers Syndrome	19, 26 May – Maroubra
Supporting challenging behaviour in young children	19 May – Peakhurst
Who wants to know about Down Syndrome?	25, 26 May – Maroubra
Supporting challenging behaviour in school age children	26, 31 May – Peakhurst
Positive practices in the classroom for children with ADHD	9, 16 June – Frenchs Forest
Teaching children with disabilities about sex and relationships	9, 16 June – Peakhurst
ADHD in the early years – understanding and responding	16 June – Miller
Understanding depression and anxiety in children and adolescents	23 June – Peakhurst
Learning Links has a number of courses which involve a fee. For more information visit their website www.learninglinks.org.au or call Dana 02 8525 8222	

Calendar continued

Family Advocacy

Phone for more information, venue details and to register on **02 9869 0866** or

1800 620 588 (free call for NSW non metro callers).

Email: workshops@family-advocacy.com or visit their website for more information www.family-advocacy.com

Moving out...
from planning to action

25th May – Yass

26th May – Cowra

27th May – Bathurst

28th May – Katoomba

In Control Australia

In Control Australia is a group of individuals and organisations who aim to bring about systemic policy change in Australia to enable individuals with disability and their families to self manage their support. They have a number of courses available through the year for more information go to their website.

www.in-control.org.au or call Ph: **08 8373 8333**

Positive Partnerships

Supporting school aged children on the Autism Spectrum www.autismtraining.com.au or call **1300 881 971**

4 & 5 May – Goulburn
registration closes March

12 & 13 May – Orange
registration closes March

25 & 26 May – Sutherland
registration closes March

8 & 9 June – Central Coast
registration closes April

16 & 17 June – Newcastle
Registration closes May

The Leukaemia Foundation

The Leukaemia Foundation holds numerous courses that are free. To find out more information go to the website www.leukaemia.org.au or contact them on **02 9902 2222**

Bookings essential to Snezana Djordjevic
Ph: **02 4226 9199**

sdjordjevic@leukaemia.org.au

Myeloproliferative Disorders

27 April – Rockdale

Carers' Health and Wellbeing

9 June – Rockdale

The Spastic Centre

Holds a range of information sessions for people with cerebral palsy and their families throughout the year. To find out more information about dates and what's on visit www.thespasticcentre.org.au

For more information call Alissa Griffiths on **02 9479 7225** or email agriffiths@tscnsw.org.au

Carers NSW

Carers NSW have a number of courses running. Check their website for current courses www.carersnsw.asn.au and look at "What's On" where you will find a list of courses available or call Lorna Downes on **0400 331 075** or **02 9289 4226**

Independent Living Centre NSW

Run courses (with a fee) covering the following Living Easier, Staying Connected, Continence Management, Easing the Pressure, Manual Handling, Wheelchair Prescription, Household Seating, Getting a Grip on Grab Rails, Mobility Aids and Vehicle Modifications. Check the website for further details www.ilcnsw.asn.au or call **1300 885 886** or **9890 0940**

Down Syndrome NSW

All enquiries and registration: contact Siena O'Brien, phone **9841 4411**

workshops@dsansw.org.au or the website www.dsansw.org.au

Behaviour Management (has a cost)

Friday 30th April Rosehill

That's what friends are for (has a cost)

Saturday 1st May Rosehill

