

MINUTES
SYDNEY CHILDREN'S HOSPITAL, RANDWICK
PARENT & CONSUMER COUNCIL MEETING
Tuesday 11th August, 2009
Executive Unit Meeting Room SCH at 6:00 pm

Purpose of the SCH PCC: *To promote child & family friendly health care through the involvement of consumers in decision making.*

1. **PRESENT:** Melinda Pickard, Parent Rep & Co-Chair
Phyllis Moran, Director of Nursing & Co-Chair
Michelle Honan, Patient Friend
Vanessa Costa, Parent Representative
Minn Simpson, Regional Parent Rep (via teleconference)
Lisa Wellington, Regional Parent Rep
Stacey Gerritsen, Parent Representative
Lif O'Connor, The Greater Metropolitan Clinical Taskforce (Transition Care Program) Representative
Kate Bishop, Association for the Wellbeing of Children in Healthcare (AWCH) Representative
Rita Chater, Parent Representative Inflammatory Bowel Parent's Group
Walter De Ruyter, Manager Community Partnerships
Adam Check, Chief Executive, Sydney Children's Hospital Foundation
Dr Susan Adams, Paediatric Surgeon
2. **APOLOGIES:** Les White, Fay Chiotis, Anne Cutler, Hala Katf, Jennifer Mirto, Deidre Kennedy, David Loy, Toni Stewart & Merron Howard
3. **MINUTES:** 12th May, 2009 accepted – Lif O'Connor & Melinda Pickard
4. **Changes to Committee Membership:**
 - 4.1 **Welcome:**

Adam Check was welcomed as a new member of the Committee and gave brief overview of the Sydney Children's Hospital Foundation which is the principal fundraising body for the Sydney Children's Hospital. The Foundation engages the community and provides philanthropic opportunities for partners to be directly involved with the Hospital and make a difference in the lives patients and families. The Foundation advocate for the Hospital and work together to gain exposure in political and public arenas. The Foundation focus their efforts on the purchase of equipment, the construction and refurbishment of facilities and the funding of clinically-based research endeavours. Adam explained that he is keen for Foundation staff to be more aware of the workings of the hospital on the ground level and is looking forward to be more involved through the Sydney Children's Hospital Parent and Consumer Council.
5. **BUSINESS ARISING:**
 - 5.1 **Handy Hints Booklet for Parents with Complex Children: S Burrett**

Stacey had mentioned the brochure "Through the Maze" which is a guide to benefits and services for families of children with a disability and suggested that this would be greatly beneficial to families. Sara explained that this brochure is given out to families who have a child with a disability through the Social Work Department or is available on line. A discussion ensued on how to make sure that all families are able to receive this information – especially if they do not have a social worker.
Action: Sara to add the website for Through the Maze onto the Social Work Brochure.
Action: Sara will organise a wider distribution of the social work brochure to include all wards.

5.2 Adolescent & Child Engagement: P Moran

5.2.1 Adolescent Representatives for SCH PCC:

Phyllis explained the difficulties in recruiting adolescents to join committees and that more work needs to be done in gaining child and adolescent feedback. Over the next month Michelle & Jackie Ludher will coordinate an adolescent survey for inpatients over the age of 12 years. This survey is being run in conjunction with other children's hospitals in Australia so we will be able to compare services, learn from each other and together look at ways we can improve the experience of young people in hospital.

6. STANDING ITEMS:

6.1 Transition Update: LO'Connor

Noted.

6.2 CCC&BD: L Wellington

Lisa mentioned that the biannual event Kids Cancer Update will be held at SCH on the 30th August.

6.3 Action Spreadsheet: M Honan

Noted.

7. NEW BUSINESS:

7.1 Proposed New Building Update: D Loy

Deferred until the November 10th Meeting.

7.2 Environmental Group (SCH): S Adams

Dr Susan Adams explained that the SCH Environmental Group was formed one year ago with staff who are interested in the future of the planet and the way in which it is left for our children. Dr Adams discussed the issues that have been addressed through the Environmental Group so far which include, recycling, proposed new building and energy use. Staff have been encouraged to turn off their computers at the end of the day.

Dr Adams asked the parents on the committee on whether they could support the recycling initiative in the wards. Members agreed that the best way in which to remind staff, families and children to recycle is to have color coded bins that are clearly labeled as to which bin is for paper and other waste. Currently this is not available throughout the hospital wards and parents kitchens. Dr Adams also invited this committee to let the Environmental Group know via Michelle if they have any other thoughts in how to make the hospital a greener place.

Action: David Loy to follow up with John Nye on whether the coloured bins would be available to use with our current waste management contractors.

7.3 Overview of Community Partnership: W de Ruyter

Walter provided an overview of the role of the Community Partnerships Division which ensures greater involvement by local communities and key stakeholders in the planning and delivery of their health care within South Eastern Sydney Illawarra Area Health. The division has Area responsibility for: Consumer participation, including the Area Health Advisory Council and Consumer Advisory Committees, Non Government Organisation Grants Administration, fundraising, sponsorship. These functions have significant consumer and community involvement for South Eastern Sydney Illawarra Area Health and in assisting with Caring Together Implementation Plan.

7.4 Inaugural Consumer Advisory Committee Forum: W de Ruyter

Walter spoke of the Inaugural Joint Consumer Advisory Committee Forum which was held on the 7th July with a wide range of representatives (minutes attached). Melinda and Michelle attended this meeting as SCH representatives. Melinda found this forum very valuable and gave her a better understanding of how other Family Advisory Councils are run and an opportunity to share ideas.

7.5 Joint Meeting Westmead Family Advisory Committee & Sydney Children's Hospital Parent & Consumer Council: P Moran:

Phyllis gave a brief summary surrounding the joint meeting of the Family Advisory Councils from both Westmead Children's Hospital and Sydney Children's Hospital held on the 15th

May, 2009. Phyllis explained that all who attended agreed that it was a valuable meeting. This was an opportunity to share ideas and discuss structure, terms of reference and past and current projects. Members of the Sydney Children's Hospital Committee were extended an open invitation to attend Family Advisory Committee Meetings at Westmead Children's Hospital.

7.6 Sydney Children's Hospital Parent & Consumer Council Profile: M Pickard

Melinda spoke of the joint meeting with Westmead Family Advisory Committee and Sydney Children's Hospital Parent & Consumer Council as a very positive experience.

Melinda said that listening to their members it became apparent that Westmead Children's Hospital seem to utilize their Family Advisory Committee Council in a more productive way with many representatives on various committees and consultation in decision making across the board. Melinda asked the question - how can we raise the profile of Sydney Children's Hospital Parent & Consumer Council to encourage more consultation which would benefit both families and staff? Michelle has already discussed this issue with Les who has encouraged the Publications Committee to seek comments/advice on any document or publication being put together for parents and carers. Phyllis will also contact the Policy Pathway Guidelines Committee to try and encourage consultation with the committee.

Action: Phyllis to follow up with the Pathway Guidelines Committee.

Action: Phyllis to discuss with management.

7.7 Self-Evaluation Model & Tool on the Respect of Children's Rights in Hospitals and Health Services: S Burrett

Sara explained to the members that Les had attended The International Network of Health Promoting Hospitals & Health Services Task Force on Health Promotion for Children and Adolescents. The self-evaluation tool on the respect of children's rights in hospital was developed with the participation and collaboration of all the Task Force Members, through preparatory meetings, discussions and the implementation of a pilot test in order to further improve the tool before dissemination. Les has convened a working group to pilot this tool at Sydney Children's Hospital and plans to report at the November CHA Conference.

7.8 United Kingdom's National Health Service Annual Conference: L Wellington

Lisa Wellington attended the National Health Service (NHS) Conference in Liverpool, UK in June as part of the Australian College of Health Service Executives (ACHSE) delegation. Lisa felt of particular interest were the trends in how the UK is managing current health care challenges. Lisa felt that they are successfully using initiatives which collaborate with the private sector - such as the LIFT program - which invites investment from the private sector to build state of the art medical facilities, and then the government rents it back from them for a guaranteed 20 years. This is allowing faster building of more modern facilities to meet increasing demand, without creating the overhead of facilities management. The government has outsourced the palliative care function to not-for-profit organisations such as the Sue Ryder Foundation and Marie Curie who operate hospice facilities, in home palliative care nursing, and palliative care training and accreditation programs nationally. More partnering with the private sector to support people in their homes includes successful ventures with companies such as Bupa. In summary, the government has realised that they do not have the resources so they are collaborating with the non-government sector in the delivery of health care services.

7.9 Parent & Carer Resource Room: S Barrett

Sara spoke of the great benefit parents and carers would receive if we had the opportunity to use a space for a Parent and Carer Resource Room. The Resource Room is somewhere parents and carers could take "time out" and source information about a range of services which is usually run by a volunteer. Michelle mentioned the Family Room that is planned for the new building will probably include resources and information for parents and carers. Melinda suggested that the waiting area outside admissions could be a useful space in the interim to place information for parents and carers.

Action: Michelle to follow up with David Loy

7.10 Caring Together – The Health Action Plan for NSW: P Moran

Phyllis spoke of the initiatives that Sydney Children's Hospital is working on in response to the recommendations of the Caring Together Health Action Plan for NSW:

- Name badges for all staff are being organised.
- Nursing Unit Managers have had their photos framed and placed in all wards
- Sydney Children's Hospital Clinical Council to be established which will give clinicians an opportunity to be more involved in decision making
- Deteriorating Patient Project rolling out across Area
- Discussions are taking place around the establishment of a Children's & Young People's Health Authority (New South Wales Kids)

7.11 Implementing a PACS System:

Stacey spoke of the Paediatric Ambulatory Care Service in the Campbelltown area that is available to children with multiple disabilities that may need minor procedures eg: peg changes. This service allows the children to have their procedures done quickly and efficiently without taking up places in the Emergency Departments. Phyllis explained that there has been a reorganization of the Outpatients Department to try and make this service more efficient and that there have been discussions on using a space in OPD for such a service.

Action: Phyllis to keep the Committee informed on progress.

7.12 HELP Centre Charges:

Sara explained that there will be an increase in loan charges for equipment through the HELP Centre from the 1st September. Sara said that there had been an initial request to stage the price increases but this has been rejected. One of the issues surrounding the price rise was that equipment had not been returned to the HELP Centre and staff were hoping with the increase deposit that this would encourage parents to return equipment. Parents on the Committee raised their concern as they feel that there will be some families that will not be able to pay for this sharp increase in deposits. Sara explained that any families who are in financial difficulty will be referred to Social Work for assistance.

Stacey raised the issue that there are companies who supply pumps free of charge when ordering feeds through them. Families may need a referral through the dietitian or CNC.

Action: Sara to follow up with Helen Kepreotes.

8. FOR YOUR INFORMATION:

8.1 "What to expect when going to hospital" : D Kennedy

Noted.

Michelle Honan

Patient Friend

Sydney Children's Hospital