

MINUTES
SYDNEY CHILDREN'S HOSPITAL, RANDWICK
PARENT & CONSUMER COUNCIL MEETING
Tuesday 10TH February, 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
Les White, Executive Director
Michelle Honan, Patient Friend
Vanessa Costa, Parent Representative
Sara Burrett, Head, Social Work Representative
Rebecca McDonald, Respiratory CNC
Lisa Wellington, Regional Parent Rep (via teleconference)
Fay Chiotis, Parent Representative
Minn Simpson, Regional Parent Rep (via teleconference)
Lif O'Connor, GMTC Representative
Anne Cutler, AWCH Representative
Merron Howard, CCC&BD Parent Advisory Group Representative
Stacey Gerritsen, Parent Representative

2. **APOLOGIES:** Hala Katf & Ross Johnston.

3. **MINUTES:** 11th November, 2008 accepted – nil changes.

4. **Changes to Committee Membership:**
 - 4.1 **Resignation:**
Unfortunately due to ill health Tanya Carnegie has resigned from the Committee. The Committee wishes to thank Tanya for her contribution and wishes her a speedy recovery

 - 4.2 **Parent Representative Co-Chair:**
Phyllis enquired whether there was any interest from the parent representatives to fill the position of Co-Chair. Melinda Pickard put forward her interest in this position and the Committee unanimously accepted. Congratulations Melinda.

5. **BUSINESS ARISING:**
 - 5.1 **Parent's Meals: A Cutler**
Phyllis gave a brief overview of the Children's Hospitals Australasia Consumer Liaison Special Interest Group Survey Results 2008 surrounding the issues of meals for parents and parking: only 44% of hospitals surveyed own/manage their car parks and most hospitals provide some type of concession for parking fees.

70% of hospitals provide breastfeeding mothers with meals but very few feed other parents. All provide tea, coffee and an area where parents can prepare food. All provide some type of accommodation for parents. Only ½ of the hospitals provide internet access and many that do, charge by the minute.

When asked what negative feedback they received, it seems that we all have the same issues – parking, lack of provided meals, food expensive & lack of family accommodation.

 - 5.2 **Parking: S Burrett:**
No further information at this time surrounding the meeting with Metro Parking. Anne pointed out that Scotland has abolished all costs of parking across the country for patients and families visiting hospital facilities with Wales to follow shortly.

Phyllis explained that unfortunately Sydney Children's Hospital does not own their car parking facility and will be unable to follow this lead. Parents noted that the five day pass which is a little cheaper is noted in the Handy Hints brochure. Sara also explained that families who are suffering financial hardship are eligible for concession parking which is organised through the Social Work Department. Fay stated that not all families would be aware of this and may be too proud to ask for help. Fay explained that when her son was admitted to Intensive Care for many weeks she was not aware of this option and it may be helpful to advertise these two options in the parent rooms of the Children's Intensive Care Unit.

Action: Sara to organise flyer.

5.3 Family Accommodation on Weekends at Ronald McDonald House: P Moran

Phyllis & Sara are planning to meet with Peter Schneider from Ronald McDonald House in the near future for further discussion. Sara mentioned that the Social Work Department had received an increase in requests for subsidized meal vouchers when the petrol prices were at their highest.

Action: Phyllis to follow up with Peter Schneider..

5.4 Concealment Trolley: P Moran

Phyllis was happy to report that OH&S matters surrounding porters accompanying the patient and family to the morgue had been discussed with the appropriate staff. It was decided that smaller patients could be transported in a pram and larger patients in their own bed. It was also decided that a nurse will accompany the family if the child needs to be prepared. It was also agreed upon that the entrance to Children's Intensive Care Unit via the parents waiting area would no longer be used if patients need to be transported to the morgue. The Committee was very happy with these changes.

Action: Sara to inform Social Workers of these planned changes in practice.

5.5 Smoke Free Zone: S Burrett

The committee noted that the High Street area surrounding the hospital has been kept clean of cigarette butts.

5.6 Handy Hints Booklet For Parents with Complex Children: S Burrett

Fay and Stacey spoke of the Victorian booklet "There is no such thing as a silly question" as well as brochures from Learning Links. Les thought that it may be useful to actually adapt one of these brochures with services for NSW rather than start from scratch. Fay thought that the Learning Links brochures were very comprehensive. Les suggested that AWCH may be interested in the adaption of a NSW booklet.

Action: Anne to follow up with AWCH

Action: Sara to follow up with Learning Links.

5.7 Signage from POWH Emergency Department to SCH Emergency Department: L White

Les has had discussion with Mr Loy and appropriate staff from POWH. They feel that the current signage on the perimeter and campus is clear and adequate. If a paediatric patient mistakenly arrives at the adult Emergency Department for urgent treatment it would be responsible for the staff to attend to the patient immediately before transferring to SCH. Les is happy to revisit this issue if any problems arise.

5.8 Vera Adderley Residence POWH: S Burrett/ L White

Sara mentioned that the Social Workers have been informed that they are only allowed to book families into the Vera Adderley residence up until the 7th March 2009 which will leave fewer options for accommodation for all families on site. A discussion ensued surrounding the difficulties this will mean for all families and Social Work staff in finding affordable options around the hospital for accommodation.

Les suggested that it may be worthwhile discussing this issue with the Foundation for assistance. Also discussions surrounding subsidized accommodation with the Coogee Bay Hotel, Gemini Motel & Crowne Plaza maybe useful.

Action: Sara to liaise with local facilities re subsidized accommodation & SCH Foundation.

Action: Les to discuss with Campus Management.

5.9 Additional HELP Items Required by Parents: M Honan

Michelle discussed this issue with Virginia Binns who explained that the HELP Centre provides specialised consumable items that are not readily available at supermarkets and commercial pharmacies. Most of the items that Stacey had listed are readily available at those venues. The biggest problem though was space and unfortunately Virginia said that there is not enough space to store any more items. Stacey did acknowledge that these products could be purchased outside but that parents were charged around five times higher than if purchased through the hospital. Stacey wondered whether the hospital could sell these products to parents at a cheaper rate than outside departments and still make a profit for the hospital which will also assist families with the cheaper cost. Vanessa asked the question whether it would be possible for the hospital to work with a company such as Independent solutions in taking orders and payment from families and then having the company mail out directly to the families. This would allow the hospital to charge an administrative fee and make a profit as well. Les has asked Michelle to approach Virginia to explore these options further.

Action: Michelle to follow up with Virginia.

5.10 Communication Between Treating Teams: L White

Les noted that the issues raised surrounding communication between treating teams have been tabled at the Quality Improvement Management Group. Les explained that this Committee is where planned quality improvement projects are discussed which included the Coordinating Clinician Project. Stacey felt that being allocated a Coordinating Clinician works better if they are a staff specialist who is on site rather than a Visiting Medical Officer. Though a double approach of having a Coordinating Clinician at SCH and also one at your child's hospital of origin works well with case management.

Les spoke of the recent NSW Health Patient Survey which is conducted annually throughout New South Wales. Les gave a brief overview of the recent summary written which indicates in all measures of care that Sydney Children's Hospital rated extremely well. Sydney Children's Hospital was ranked against our peer groups and across the state as a whole which resulted in very positive feedback. Les feels that one of the reasons that the hospital has performed so well is because of the feedback gained through listening to parents and carers as well as the involvement Parent & Consumer Council. Les also explained that we will review areas for improvement and this will be progressed through the Quality Improvement Management Group.

6. STANDING ITEMS:

6.1 Transition Update: LO'Connor

Lif gave an overview of the report (attached).

6.2 CCC&BD: M Howard

Merron reported that the play room refurbishments in C2 West have been finished which had been funded through donors. Work is also planned for the kitchen area.

6.3 Action Spreadsheet: M Honan

Noted.

7. NEW BUSINESS:

7.1 Carers Week 2008: M Honan

Michelle wanted to acknowledge Ross Johnston & Grahame Colditz from the Area Carers Support Office for their ongoing support in Carers Week events for parents and carers in 2008. The events held were: massage therapy, barbecue, Information Pamper Packs & afternoon tea with Damien Leigh. All were very well received.

7.2 Christmas Lunch for Parents, Carers & Siblings: M Honan

Thanks to a generous donation from the Coles Staff Association Michelle was able to again organise vouchers for parents, carers & siblings to enjoy Christmas lunch at the Fourecourt Café - fifty six adults and 24 children took up the offer for lunch.

- 7.3 Patient Hand Held Record: P Moran**
Phyllis recently finalised a draft Patient Hand Held Record which was created as a result of a request from the Parent & Consumer Council for some type of framework where parents & carers could keep records of their chronically ill child's treatments and history. Phyllis realises that there is already an Oncology and a Cystic Fibrosis version and probably many more, however this one is generic and can be adapted to any speciality. Phyllis thanked the Committee members for their very useful feedback and has also sent it out to the Management Group as well. It is planned for this document to be available for parents and carers via the Sydney Children's Hospital website which will allow any additional pages to be printed off when needed.
- 7.4 AWCH Conference: M Howard**
Merron & Anne wanted to thank and acknowledge Ross Johnston in organising the financial support for parents from the Parent & Consumer Council to attend the recent AWCH Conference
- 7.5 Security Issues C3 South: V Costa**
Vanessa wanted to raise the issue of patients in C3 south that abscond which leads to nursing staff having to search for these patients. Vanessa wanted to know if there were any plans to have a swiper system in place for C3 South.
Action: Phyllis to follow up with David Loy.
- 7.6 Review of SCH PCC Terms of Reference & Strategic Plan: M Howard**
Merron brought up the subject of reviewing the SCH Parent & Consumer Council Terms of Reference and Strategic plan. Committee members agreed.
Action: This review will be organised at one of our regular meetings this year.

Michelle Honan
Patient Friend
Sydney Children's Hospital