

**MINUTES**  
**SYDNEY CHILDREN'S HOSPITAL, RANDWICK**  
**PARENT & CONSUMER COUNCIL MEETING**  
**Tuesday 12<sup>th</sup> August, 2008**  
**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:** Lyn Peek, Parent Rep & Co-Chair  
Phyllis Moran, Director of Nursing & Co-Chair  
Michelle Honan, Patient Friend  
Merron Howard, CCC&BD Parent Advisory Group Rep  
Melinda Pickard, Parent Rep  
Stacey Gerritsen, Parent Rep  
Sara Burrett, Social Worker  
Anne Cutler, AWCH Representative  
Lisa Wellington, Regional Parent Rep  
Minn Simpson, Regional Parent Rep  
Ross Johnston, Area Manager, Consumer Participation
2. **APOLOGIES:** Les White, Tanya Carnegie, Hala Katf, Rebecca McDonald & Vanessa Costa.
3. **MINUTES:** 13<sup>th</sup> May, 2008 - accepted - nil changes.
4. **Changes to Committee Membership: Nil**
  - 4.1 **Resignation:**  
Lisa Broadley has taken up a new position as Community Engagement Officer with the Multicultural Health Service. Ross Johnston will be attending the SCH Parent & Consumer Council Meetings until a new Consumer Participation Officer has been appointed.
  - 4.2 **New Committee Member:**  
The Committee welcomed Raelee (Minn) Simpson to the Committee as a Regional Parent Representative who will be most of the time joining the meeting via teleconference from Dubbo.
5. **BUSINESS ARISING:**
  - 5.1 **Security C1 South & C2 South: H Katf**  
No update available at this time.
  - 5.2 **Parent's Meals: A Cutler**  
Anne explained that Children's Hospitals Australasia has started to put together a questionnaire re Parent's Meals in hospitals to obtain further information as to what other facilities are offering parents.
  - 5.3 **Internet Kiosk Facilities: L Peek**  
Lyn noted that there were still access issues for children in wheelchairs to use the Internet Kiosk facilities at the Star Café. Children in wheelchairs can only use the lower kiosk as they cannot reach the higher one and where the lower kiosk is positioned currently it is impossible for a parent/carer and child in a wheelchair to use this kiosk.

If the Kiosk's were swapped around and placed back to back to each other this would allow easier access as there would be more room. One of the fixed tables in the café may have to be moved as well to allow access for a child in a wheelchair and a parent or carer who may have to assist with the internet.

***Action: The issue to be raised with Mr Loy to seek his recommendations.***

**5.4 Parking: S Burrett**

Sara reports that Metro Parking have not returned any of her calls and therefore she has not been able to organise a meeting.

**5.5 Family Accommodation Ronald McDonald House: M Honan**

Michelle reported that Penny Douglas is happy for this initiative to go ahead. Flyers will be placed in parent's kitchens offering Friday & Saturday night accommodation to parents and carers who have children currently admitted to Sydney Children's Hospital. This may allow long term families to catch up with their spouse or siblings. The cost of these rooms will be \$33.00 per night. Inpatients requiring isolation due to transmissible infections are not eligible. Parents and carers can book direct with Ronald McDonald. This offer will depend on room availability.

**Action: Michelle to organise flyer.**

**5.6 Concealment Trolley: P Moran**

The issues surrounding the concealment Trolley were raised at the Palliative Care meeting. It was agreed that the sight and sound of the trolley can be quite confronting and upsetting to parents, patients and in fact staff in general. It was agreed that when the trolley needs to access the Intensive Care Unit the door near the parents lounge should not be used. The issue of using a patient's bed was discussed and could be looked at in the future as there would be OH&S issues to be considered.

**Action: Phyllis to discuss further with the Palliative Care Team.**

**5.7 EFTPOS for Cashier & Pharmacy:**

David Loy is looking into the costs of using this service.

**Action: David Loy to follow up.**

**5.8 Smoke Free Zone: S Burrett**

Sara has raised this issue with the Occupational Health & Safety Committee who were looking into asking the cleaning staff to clean the footpath in front of the hospital on a weekly basis. The Committee felt that this area was Council property and that they may be able to assist with a solution.

**Action: Sara Burrett to discuss this issue at the OH&S Committee.**

**6. STANDING ITEMS:**

**6.1 Transition Update: L O'Connor (attached)**

Lif gave a brief overview of the following points:

- The background for the formation of the SESIAHS Transition Care Committee.
- The Starlight "Livewire" pilot project at SCH.
- The Transition Awareness Week activities.
- The funding enhancement from the DOH for adult services for Spina bifida and Genetic Metabolic diseases.

**6.2 CCC&BD: M Howard**

Nothing to Report at this time.

**6.3 Action Spreadsheet: M Honan**

Noted. The Committee has requested that the action spreadsheet as well as the minutes be put onto the SCH website.

**Action: Michelle to organise with Sean Lawless.**

**7. NEW BUSINESS:**

**7.1 Area Wide Youth Consultancy Committee: Lif O'Connor**

This is an initiative arising from the presentation to the SESIAHS Clinical Council. It will act as an advisory body to paediatric and adult facilities across the area. The first priority will be to identify the ten areas with most difficulties.

## 7.2 Family Advisory Questionnaire: P Moran

Phyllis explained that Sydney Children's Hospital was asked to participate in a global questionnaire re Family Advisory Council Programs at Paediatric Hospitals. The majority of hospitals contacted structured their Committees in quite similar ways. Variations in terms of member numbers, recruiting techniques and orientation practices were not very different. The greatest hospital to hospital variation was found in terms of what departments were represented by staff. The overwhelming majority of surveyed hospitals felt that the Family Advisory Committee Programs were useful and important tools. The overwhelming majority of surveyed hospitals indicated that their programs were in a constant state of evolution, whether they be through mandated turnover, self evaluation and adjustment or simply increased effectiveness as parents become more confident and aware of hospital operation.

## 7.2 Translated Sydney Children's Hospital Handy Hints Brochure: M Honan

Michelle reported that the hospital has finally received their translated versions of the Handy Hints Brochure in Arabic, Chinese and Vietnamese. The committee wanted to know whether these would be available to load onto the website.

**Action: Michelle to see advice from Sean Lawless.**

## 7.4 Feedback from Ward Based Suggestion Boxes: M Honan

Report noted - Michelle explained that this report has also been forwarded to the Quality Improvement Management Committee as well as the SCH Department Heads. Michelle explained that as the feedback forms are collected any urgent or important issues are forwarded to appropriate staff at the time of collection to be addressed.

- ◆ ***"Monitors should be installed in the isolation rooms as nurses cannot hear if alarms"***

Lyn reported that there are still concerns with monitors not being heard in the side rooms. Michelle said that this issue was being followed up by Cathy Lovell.

**Action: Michelle to follow up with Cathy Lovell.**

- ◆ ***"Should there be IV teams who only do IV insertions for long term patients with difficult access".***

Stacey noted that this issue was still very difficult for patients with bad access especially on weekends and evenings. Phyllis explained that there was currently a new policy being developed for "Difficult IV Access".

**Action: Phyllis to follow up in Management Committee.**

## 7.5 Handy Hints Booklet for Parents with Complex Children: S Gerritsen

Stacey felt that it would be very useful for parents & carers to have access to a Handy Hints Booklet for children with complex needs. A conversation ensued as to how difficult it is for parents and carers of newly diagnosed chronic complex children. There is so much for the parent/carer to take in and a list of hints/information would be very useful. Stacey has put together a list of hints/information and contacts that she has found useful. Include information and tips on:

- ◆ Commonwealth Respite Care Service
- ◆ DADHC
- ◆ Prescription Record Card
- ◆ Tax Benefits
- ◆ Local GP
- ◆ HEN (Home Enteral Nutrition)
- ◆ Advice on how the Allied Health dept at SCH works
- ◆ How the Pharmacy works

Ross also mentioned the Association of Genetic Support of Australasia Inc. (AGSA). AGSA provides a wealth of support and information covering some 450 genetic conditions, many of which are very rare. The committee thought that this would be an excellent initiative. Sara offered to speak with the Social Work Quality Committee to come up with a draft document to bring back to the Committee.

**Action: Sara to discuss with Social Work Quality Committee to create a draft document.**

**Action: Michelle to forward Stacey's document & AGSA information to Sara for inclusion in the discussions.**

#### **7.6 AWCH Participation Evening: S Gerritsen**

Stacey reported that she has been involved in the AWCH Participation Evening and will be joining two other families from other facilities to speak at the AWCH Conference in November. Anne explained that the families will be presenting their stories to the conference and will participate in a Low Cost/No Cost Solution Workshop. Anne is keen to encourage more parent involvement in AWCH. Anne also raised the issue of still trying to find a sponsor to cover the costs for these parents to attend the workshops. Ross has kindly offered to look into assistance for sponsorship.

**Action: Anne to seek sponsorship for parents to attend the workshop through the Carers Grant Funds.**

#### **7.7 RHW Consumer Group: L Peek**

Lyn explained that at the AHAC Consumer Meeting she attended Professor Bill Walters of the Royal Hospital for Women raised the issue of difficulties he was having in trying to gain consumer membership for the Committee. Lyn clarified that she did not mean for the RHW to join the SCH Parent & Consumer Council but that we may be able to assist in advertising at SCH. Ross said that he was aware of this issue and that there had been further discussions between himself, Helen Gunn & Professor Walters who have come up with new strategies to reach a wider network of promotion to engage participants for the committee.

#### **7.8 Signage outside POWH Emergency Department: L Peek**

Lyn explained that there had been two incidents recently of children being rushed to POWH Emergency instead of SCH Emergency. Lyn said that on the outside of POWH Emergency Department it just says "Emergency". Lyn said that this can be very confusing for families of children who may think that they are arriving at SCH Emergency. Lyn suggests that there should be clear signage stating that this is POWH Emergency Department.

**Action: Michelle to forward these issues to Mr D Loy to address with POWH.**

#### **7.9 Vera Adderley Residence: L Peek**

Lyn said that a number of parents have had discussions with her about the difficulties they found staying at the Vera Adderley Residence. Sara agreed that Social Work Department have also received many complaints about these issues which include:

- ◆ Cleanliness
- ◆ Cockroaches
- ◆ Security
- ◆ Shared male and female showers

Parents who come back to the residence in the evening usually find other people hanging around outside and just come in when parents swipe entrance to the building and parents don't feel safe in asking who they are and whether they are suppose to have access.

Parents have noted that the bathrooms and kitchens are very dirty and there is a definite cockroach problem.

Mums and young adolescents don't feel comfortable showering in the same area as men.

**Action: These issues to be forwarded to David Loy to raise with POWH.**

### **8. OTHER BUSINESS:**

#### **8.1 Additional HELP Items Required by Parents: S Gerritsen**

Stacey gave a brief list of items that she thought would be tremendous help to parents if they could be offered at a reasonable price through the HELP Desk at SCH. These items included: Bambolina nappies, protein testing sticks, Convene Critic Barrier Cream, 123 Paste (SCH recipe), Stomahesion Powder, Micropore Tape, Alco Wipes, 10ml Sterile Water & Remove Wipes.

**Action: Michelle to forward list of items to Virginia Binns for advice on whether they can be offered through the HELP desk.**

**8.2 Contacting SCH Outpatient Department for appointments: M Pickard**

Melinda wanted to highlight the amount of time it takes to try and get through to the SCH Outpatient Department to try to make an appointment. Melinda said that you often have to ring more than once because you can hang on for at least ½ an hour and often then the phone will cut out. The issue of the recorded message was also discussed with parents feeling that if they have to wait on the phone for such a long time it would be more beneficial to hear about the services that are available at SCH rather than the current recorded message.

**Action: Michelle to forward these comments/suggestion to Dr M Brydon.**

**8.3 Breast Feeding Room: P Moran**

Phyllis reported that the Breast Feeding Room has now opened on Level 0 opposite the SCH Outpatients Department. This room is available for parents, carers and staff. Entry will need to be gained via a staff member through swiper access. There is a breast pump available but parents and staff need to bring their own consumables.

**NEXT MEETING: Tuesday 11<sup>th</sup> November, 2008.**

Michelle Honan  
Patient Friend  
**Sydney Children's Hospital**