

MINUTES
SYDNEY CHILDREN'S HOSPITAL, RANDWICK
PARENT & CONSUMER COUNCIL MEETING
Tuesday 11TH May, 2010
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:**
 - Phyllis Moran, Director of Nursing & Co-Chair
 - Les White, Executive Director
 - Michelle Honan, Patient Friend
 - Vanessa Costa, Parent Representative
 - Rita Chater, Parent Representative
 - Lisa Wellington, Regional Parent Representative
 - Merron Howard, Centre for Children's Cancer & Blood Disorders
 - Parent Advisory Group Representative
 - Hala Katf, Staff Specialist Paediatrician
 - Lif O'Connor, The Greater Metropolitan Clinical Taskforce (Transition Care Program) Representative
 - Anne Cutler, Association for the Wellbeing of Children in Healthcare (AWCH) Representative
 - Deidre Kennedy, SESI Community Partnerships Officer, Northern Network
 - Jennifer Mirto, Nursing Unit Manager C2 South
 - Catherine McKersie, A/Head Social Work Department

2. **APOLOGIES:** Minn Simpson, Fay Chiotis, Melinda Pickard, Kellie Wogas, Robyn Bignall & Adam Check.

3. **MINUTES:** 9th February, 2010 accepted – Phyllis Moran & Lif O'connor.

4. **Changes to Committee Membership:**
 - 4.1 **Resignation:**

Michelle reported that Stacey Gerritsen has submitted her resignation from the Committee as the family is planning to move back to New Zealand. Stacey has been a valued member of the Committee since November 2006 and we would like to thank her for her outstanding contribution.

Action: *Michelle to organise a letter of thanks to be sent.*

5. **BUSINESS ARISING:**
 - 5.1 **Young Consumers on the Parent and Consumer Council: M Honan**

Michelle is currently having discussions with former patients of Sydney Children's Hospital who may have an interest in joining the Committee.

 - 5.2 **Private or Public Options: L White**

The two draft letters that were circulated explaining private or public options were discussed and the committee felt that they are both appropriate to send out to families. Deirdre did suggest a slight change of wording to Les's letter. Rita felt that the correspondence would encourage parents to use their private health insurance. All parents acknowledged how helpful Nola has been when assisting families with account issues. Les asked the committee members to forward any suggestions they may have that could assist the hospital to encourage families to use their private health insurance.

Action: *Please email Michelle directly with any comments/suggestions.*

Action: *Michelle to email suggested change to Tracey.*

Action: *Les to follow up with David Loy to ask staff to use the letter more widely when sending out paperwork for booked admissions.*

6. STANDING ITEMS:

6.1 Transition Update: LO'Connor

Transition report noted.

Lif would like to remind consumers that the Consumers Health Forum of Australia have many opportunities where they can contribute and the council will cover all expenses and also pay members for their time. Lif often attends meetings as an AWCH & SCH representative to advocate for children and young people and feels that it would be valuable to have parent representation especially for the younger age group eg: less than 16yrs..

6.2 Centre for Children's Cancer & Blood Disorders: M Howard

Nothing to report at this time.

Action: Michelle to follow up with Helen Knox re: CCC&BD minutes being tabled at the SCH PCC Meeting.

6.1 Community Partnership Update: D Kennedy

Deidre spoke of the launch at St George Hospital of the SESIAHS Disability Action Plan 2010 – 2015 and the launch of the SESIAHS Carers Pack. Deidre also spoke of her involvement in the making of an aged care planning DVD for Prince of Wales Hospital. A discussion ensued as to whether the children's hospital would benefit from making an educational and support DVD for parents and carers. Les suggested that if this was the case that this should be organised statewide and would add this item on the next Joint Family Advisory Committee meeting with Westmead Children's Hospital. Deidre also suggested the Committee may like to invite Janice Oliver to attend one of our Committee meetings to discuss the carers pack and explain her role as the SESIAHS Carers Program Manager.

Action: Deirdre to circulate SESIAHS Carers Pack.

Action: Les to raise the DVD issue at the next Joint Family Advisory Committee Meeting.

Action: Michelle to organise invitation for Janice Oliver to attend a PCC Meeting.

6.4 Caring Together: P Moran

Phyllis gave a brief update and explained that the Clinical Handover Project has commenced where nursing staff are already including safety checks. Between the flags project is also progressing well both at CHW & SCH. This is a statewide initiative which introduces an emergency response system called Between the Flags which ensures that any child whose condition may be deteriorating will receive prompt and appropriate care. If the child's observations enters a coloured zone it alerts the nurse to possible deterioration and they should then contact medical staff for a clinical review. Once the parents & carers information letter is finalised this will be placed in the bedside information pack as well as included in the paperwork sent to parents and carers on booked admissions. A project officer will be engaged to review and investigate calls to find out if anything could have been handled better.

6.5 Action Spreadsheet: M Honan

Noted.

Action: Michelle to forward the complete action spreadsheet to new members.

7. NEW BUSINESS:

7.1 Between The Flags: P Moran

This item was also discussed in 6.4.

7.2 SESIAHS Carers Program: J Oliver

Janice gave a brief overview of her role as the Area Cares Program Coordinator as it stands and the wide area that she has to cover. Janice spoke of the Statewide Carers Action Plan that was put together in 2008 and the strategies for implementation by 2012. Janice also spoke of the Area Carers Grants and that Sydney Children's Hospital has applied for two this year surrounding Christmas Lunch for parents, carers and sibilnigs of patients and also assistance with catering costs towards the planned Carers Week Forum that is being hosted by the Sydney Children's Hospital, Clinical Innovatyon and SESIAHS Carers Support

Program. Janice was also keen to assist the hospital in the purchase of Through The Maze Resource books that would be available to parents and carers through the Social Work Department. This will be greatly appreciated by families of newly diagnosed patients who are often overwhelmed at this time and will find this a great resource and assistance. Lyn wondered whether these books could be sold through the HELP desk. A discussion ensued as it was decided that the brochures for this resource would be made available in the HELP centre as well as all wards.

Action: Michelle to follow up with the HELP Centre.

7.3 Cystic Fibrosis Peer Review: M Pickard

Melinda explained that she was recently invited to assist with the Peer Review of the adult Cystic Fibrosis Clinics at Westmead & Prince Alfred Hospitals. This was an initiative that was started in the United States and then the United Kingdom to imp

7.4 Parent Feedback: P Moran

Phyllis raised an issue brought up by a parent concerning the lack of an ATM machine in the SCH. Parents agreed that it would be more convenient for parents and carers if an ATM machine was available near the Staff Café rather than having to walk to Barker or High street machines in the Prince of Wales Hospital.

Action: Michelle to follow up with David Loy.

7.5 Caring for the Carers Working Group: M Honan

Michelle gave a brief overview as to this working group which consists of a small number of staff and SCH volunteers. Over the last few months this group has organised for parents and carers of SCH: family barbecue, information morning tea, head and neck massage therapy and trialed ward volunteer hosted morning teas to encourage community spirit and support amongst parents and carers. This group has also raised money through raffles and donations and has recently purchased parking vouchers to assist for families who have had a child pass away.

7.6 Partnership in Care Guideline: P Moran

Phyllis called for comments and suggestions to the Partnership in Care Guideline. A lengthy discussion ensued regarding this document. Merron suggested that it needs a clear definition. Catherine feels that the discussion between the nurse and parents should take place at every shift change as a parent may feel that they are happy to care for their child but this can change at any time due to lack of sleep, child having a bad day, receiving bad news from staff etc. Lif felt that a form should be attached as to what has been agreed upon but most parents felt that this would be too much to fill out at every shift change. It was agreed that the aspects of what clinical care parents are permitted to do should be documented and agreed upon by the medical staff and depending on what type of care may need to be monitored by nursing staff. Phyllis encouraged the Committee to take the time to review and forward all comments and suggestions to Michelle

Action: Comments and suggestions emailed to Michelle by Friday 18th June.

NEXT MEETING: Tuesday 10th August, 2010.

Michelle Honan
Patient Friend
Sydney Children's Hospital