

MINUTES
SYDNEY CHILDREN'S HOSPITAL, RANDWICK
PARENT & CONSUMER COUNCIL MEETING
Tuesday 9th February, 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:** 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
Kellie Wogas, Parent Representative
Stacey Gerritsen, 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
Kate Bishop, 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
Adam Check, Chief Executive, Sydney Children's Hospital Foundation
2. **APOLOGIES:** Minn Simpson, Fay Chiotis, Merron Howard
3. **MINUTES:** 10TH November, 2009 accepted – Phyllis Moran & Vanessa Costa.
4. **Changes to Committee Membership:**
 - 4.1 **Resignation:**
Toni Stewart has resigned from the Sydney Children's Hospital and the Committee wishes her well in future endeavors.
5. **BUSINESS ARISING:**
 - 5.1 **SCH Parent & Consumer Council Profile: M Honan**
Michelle spoke with Jessica Jaramillo, the Public Affairs Manager who had the following suggestions:
 - A break out box or line in the rolling 'news' section of the intranet could be utilised to provide information and encourage people to utilise the expertise available from the PCC for their next project etc.
 - Reminders in TWF about the PCC as per above – perhaps combining this reminder with profile of how a department/individual/team has utilised the PCC when planning an important project/change/strategy.
 - This idea of 'profiling' certain examples of PCC contributions could potentially be a semi regular part of either TWF or an email to department heads – perhaps in the form of an 'update from the PCC' - this may however be incorporated into the newly proposed PCC newsletter.
 - Updated flyers/posters in relevant staff areas.
 - 10 yr anniversary of the committee may be an opportunity to profile the committee's work at a local media level.

Jessica has updated the internal flyer and the committee has agreed on the content.
Action: Michelle to place flyers on notice boards in the wards and other appropriate areas and will liaise with Jessica.

5.2 Help Centre Charges: C McKersie

Helen Kepreotes was unable to attend the meeting but provided the following summary:

Feeds:

- ◆ The SCH Nutrition and Dietetics Department is responsible for providing feeds to all patients when admitted to the hospital and is responsible for the hospital feed budget.
- ◆ On discharge the Department will ensure that all patients on enteral nutrition and PBS feeds are linked up to the NSW Home Enteral Nutrition (HEN) & PBS schemes. The cost of the feeds via this scheme is the cheapest that is available in the state and is part of the NSW Health Enteral tender & PBS scheme.

Equipment to administer feeds - ie Pumps, Bags, Giving sets

- ◆ The SCH Nutrition & Dietetics Department is not responsible for this budget; therefore Dieticians are not responsible in dealing with feeding equipment & consumables.
- ◆ The SCH has successfully set up the Home Lending Centre. This centre is responsible to provide to patients the necessary feeding equipment & consumables. The cost of the equipment & consumables via this centre are the most competitive prices in NSW.

Over the last six month there have been a few developments:

- ◆ Some nutrition companies are currently offering FREE PUMPS. This is a new offer to consumers & not part of the NSW enteral tender. The free pump is only offered if consumers are going to use a feed that the company also sells.
- ◆ The dieticians are responsible to prescribe the correct feed based on a patients nutritional needs and decisions are not influenced by company deals.
- ◆ If however, a consumer chooses to take up the free pump deal then the consumer should ask the company to sign up for the consumables as well. It is important to point out that the cost of the consumables in the long term are very expensive when using company specific pumps.

Overall:

- ◆ SCH currently has the most competitive price when purchasing/lending feeding equipment and consumables from the Home Lending Centre.
- ◆ SCH currently is following the NSW HEN scheme which is the cheapest option at present.
- ◆ The NSW HEN GMCT group, which I am a member of, are working very hard at present to lobby for government funds to support HEN consumers requiring feeds and consumables. Will keep the hospital posted on this matter.

Action: Helen will update the Committee on any new developments,

Action: Please email Michelle directly with any comments.

6. STANDING ITEMS:

6.1 Transition Update: LO'Connor

Transition report noted.

Lif mentioned that there is an opportunity to comment on the Legislative Council enquiry into the provision of education to students with a disability or special needs and also the SESIAHS Disability Action Plan.

Action: Michelle to email out both documents to the Committee.

6.2 CCC&BD: M Howard

Deferred.

6.3 Community Partnership Update: D Kennedy

Deidre explained that she has been working on updating the Consumer Participation Website on the SESIAHS Internet site to encourage consumer participation and to make this site user friendly as well as informative for consumers. Deidre gave a brief demonstration of the internet site and discussed her thoughts on overall content. Deidre is keen to include photos and biographies of the consumers on the SCH Parent & Consumer Council, as have

the other consumer groups. Deidre feels that this website would also assist the SCH Parent & Consumer Council profile in the community. Deidre will be responsible for maintaining this website with input from the various committees and will review in 6 months and then annually. The link to the current Consumer Participation website that is under revision is <http://www.sesiahs.health.nsw.gov.au/consumers/>

Action: Please forward any feedback on the revised page for SCH and its content to Michelle

6.4 **Caring Together: P Moran**

Phyllis gave a brief overview of the SCH response to the Caring Together recommendations:

- ◆ Deteriorating Patient Project: an early detection system for deteriorating patients.
- ◆ Clinical Handover Project: standardized process for the handover of patients which can be utilized on all occasions.
- ◆ Clinical Support Officers: this role is to assist Nursing Unit Managers with paperwork, rosters, ordering etc

Jenny mentioned how she has found the assistance of the Clinical Support Officer a great help.

6.5 **Action Spreadsheet: M Honan**

Noted.

7. NEW BUSINESS:

7.1 **NSW Kids: L White**

Les gave a brief overview of the current progress regarding The Garling Report Recommendation "NSW Kids" and the potential benefits for child health and paediatric services in New South Wales. He encouraged consumers generally to use the opportunity to comment on the NSW Health website. Les also gave an invitation to all members of the Committee to attend the upcoming SCH Forum regarding NSW Kids which will be held on the 16th February.

Action: Michelle to forward details of forum to the Committee.

7.2 **Private Health Insurance Incentives: M Pickard**

Melinda mentioned that she was aware of many families that have children admitted to SCH that do not use their health insurance and wonders whether there was anything else the hospital could do to encourage families to use their health insurance. Melinda mentioned that at Prince of Wales Hospital she had heard that patients who use their private health insurance are offered tea and coffee vouchers, TV and local calls are also covered. Les explained that families of long term patients or children who have had multiple admissions who use their private health insurance are offered a no gap option which means all out of pocket expenses will be covered. All families are encouraged to use their private health insurance which will in turn help support the hospital in caring for all families in the future. Melinda & Vanessa also mentioned the difficulty for families receiving multiple accounts from pathology and have received debt collector's letters while waiting for payment of these accounts. Les also mentioned a letter that is sent out to families to explain the options of public and private admissions. Les would be very happy to hear from the committee if anyone has any thoughts to improve the way in which we can encourage families to use their private health insurance. Lisa and Stacey both had reservations about offering families who use their private health insurance special offers as they felt this could be fraught with difficulty and some possible perceptions of favouritism.

Action: Michelle to forward admission letter to consumers for comment.

Action: Committee members to email Michelle with any thoughts on improvement.

7.3 **SCH Neuromuscular Clinic Family Advisory Council: M Honan**

Michelle explained that Maria Cohelo, Social Worker and Dr Heather Johnston, Paediatric Neurologist have been instrumental in organizing the inaugural SCH Neuromuscular Clinic Family Advisory Council which met in November 2009. The Council aims to provide an ongoing opportunity for parents, carers and young people to be involved in the development of services offered by the Neuromuscular Clinic. The goal is to work together to provide high quality services that promote optimal health and wellbeing for children affected by the neuromuscular conditions.

- 7.4 Frequency of Parent & Consumer Council Meetings: M Pickard**
Melinda wanted to discuss whether the Council needed to meet more frequently. A lengthy discussion ensued and it was agreed that if there were outstanding matters to progress Michelle would organise a subgroup of the committee to meet as required.
- 7.5 SCH Parent & Consumer Council Newsletter: S Gerritsen**
Stacey thanked everyone for their response and gave a brief overview of collective comments. In general the committee thought that this was a great initiative. The group thought biannually would be a good start as it can be difficult to organise content if the newsletter is more frequent. Michelle mentioned that the Jessica, Public Affairs Manager would be happy to assist with her expertise in corporate design and knowledge. A subgroup would be organised to further discuss.
Action: Michelle to organise subgroup to meet to progress newsletter.
- 7.6 SCH Parent & Consumer Council Membership: M Honan**
Michelle reminded the Committee that as stated in the Committee's Term of Reference Consumer Membership duration of appointment is two years with the opportunity to renew. If you feel that you would like to resign from the committee rather than take up another two year appointment please contact Michelle.
Action: Committee members to email Michelle if you would like to tender your resignation from the Committee.
- 7.7 Consumers Health Forum of Australia: P Moran**
Phyllis has organised membership for the SCH Parent & Consumer Council to join the Consumers Health Forum of Australia and have a voting membership. The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. Michelle will email out information regarding feedback or forum opportunities that committee members may be interested in participating when received.
- 7.8 Young Consumers on the PCC:**
Les discussed the idea of inviting two young people who are ex patients to join the Council. The Committee agreed that it would be valuable to have a young person's perspective on issues especially if they have been ex-patients and would have a good understanding of the issues raised for discussion.
Action: Michelle to follow up.

NEXT MEETING: Tuesday 11th May, 2010.

Michelle Honan
Patient Friend
Sydney Children's Hospital