**MINUTES**

**Pacific Working Group**

Teleconference, Wednesday 10 April, 2013 at 1700 hrs

**Present:** Jane Skeen, Chrissy Bond, Isaiah Immanuel, Scott Macfarlane, Janet Masina

**Apologies:** Lochie Teague, Peter Bradbeer, Rob Corbett, Janet Mikkelsen, Simon Lala

**SUMMARY OF ACTIONS (from February/April meetings)**

|  |  |  |
| --- | --- | --- |
| 1. Forward details of expenditure for reimbursement to Simon.
 | Chrissy | completed |
| 1. Provide Chrissy and Rob and Amanda Lyver with the names of the Fiji palliative care group so contact can be made
 | Janet | completed |
| 1. Replace Janet on Pacific WG as she transitions from paediatric oncology nurse/ palliative care nurse to her new vocation as a funeral director. Janet to notify of timeline of her transition.
 | Janet, Jane | Not needed till later in the year |
| 1. The budget for the current financial year needs to include the cost of an education visit by Jane/Peter/Janet Masina /Janet Mikkelsen to Samoa to coincide with the launch of the early warning signs.
 | Jane | completed |
| 1. Consider a visit to Fiji with funding from Medical Treatment Scheme in the first half of the year.

5a: Opportunity for nursing visit to Fiji, September 2013. To apply to HSL for funding | RobChrissy | Will need to be deferred until more medical personnel in Christchurch to free up Rob’s time. |
| 1. Review triage criteria for appropriate expansion in Fiji.
 | Rob |  |
| 1. Another visit required by same team to Tonga to coincide with release of early warning signs.
 | Jane |  |
| 1. Launch Samoan Early Warning Signs in conjunction with an education visit.
 | Everyone | Planned for week 15 July 2013 |
| 1. Roll our Fijian Warning Signs but acknowledge that multiple languages (Fijian, Hindi) will make this more challenging. Christchurch team to liaise with Fijian colleagues.
 | Christchurch team |  |
| 1. Roll out Tongan Early Warning Signs by Auckland team in conjunction with Tongan colleagues and CCF Tonga. Proposed launch at PMA in Tonga
 | Auckland team | 24-27.09.13 |
| 1. Send reports for the 3 national projects to WCC in London.
 | Jane | completed |
| 1. Send Jane documentation necessary to have WCCNZ approved for overseas charitable status.
 | Simon | completed |
| 1. Organize for small group (Jane, Janet Mikkelsen and Scott) to talk to Peter Kiely for advice on how to expedite this.
 | Jane | Pending date confirmation |
| 1. Email members with login details and guideline for using portal.
 | Melissa | **completed** |
| 1. PI ALL2
 | Scott | 30.06.13 |
| 1. AML including use of arsenic
 | Peter | 30.06.13 |
| 1. NHL
 | Rob, Peter | 30.06.13 |
| 1. ALCL
 | Jane, Peter | 30.06.13 |
| 1. Neuroblastoma protocol
 | Rob | 30.06.13 |
| 1. Nutrition guideline
 | Chrissy, Isaiah | 30.06.13 |
| 1. Laboratory elements including transport of specimens
 | Peter | 30.06.13 |
| 1. Palliative Care Guideline
 | Janet Mikkelsen,Chrissy,Jane | 30.06.13 |

**PREVIOUS MINUTES**

* Confirmed minutes of last meeting (21 February 2013)

**COUNTRY UPDATES**

**Fiji**

* Weekly tele conferencing for an hour, supported by email, has continued between Christchurch and Fiji. The broader involvement of the Christchurch team has allowed sharing of the workload, and is the only workable solution at this stage until Mike Sullivan’s locum/replacement has been appointed. Dr Khalid Mahmood has been on leave for a month from Suva and cover has been provided by a senior Paediatric Registrar with oversight from Dr Joseph Kado. Around 20 patients are currently on treatment in Lautoka (7) and Suva (13). 3 new cases in the last week.
* Challenges remain with pathology and radiology results and review- as reliable reports have not been available in a “timely manner”. Recently MRIs from Fiji have been uploaded onto a CD and sent to Christchurch, for discussion at their tumour board meetings.
* Issue of Pacific Child Cancer Registration- issue of whether POND4kids suitable to the Pacific. Scott to meet with St Jude personnel in the next few weeks. Felt that each pacific country should have ownership of their own registry but there needs to be a mechanism that each NZ centre maintains a record of patient diagnosis, management, advice offered, discussions on patient care etc.
* Chrissy reported good feedback from the Fijian nursing training in December. Return visit planned for September to Lautoka and Suva (HSL to be contacted for funding) around the time of her visit with the surgical team (funded by RACS) to Suva.

**Samoa**

* Engagement remains, but still little communication from medical staff. Good relationship with Samoa Cancer Society. Recent referral via Dr Benjamin, but delays in sending imaging. Once imaging reviewed at Starship, opinion provided. Dr Benjamin reviewed child when he visited and child was in a perilous position and died 48hours later. Peter and Jane have met with Dr Benjamin and restated that Starship Blood and Cancer happy to review even before referral out of country considered.
* New hospital, built by Chinese, in Samoa due to open June/July2013, and Dr Benjamin hopes that the new imaging machines will have technology to allow digital transmission of imaging!!!
* Planned visit to Samoa by Starship team (Jane, Peter, Janet Mikkelsen) and Janet Masina (CCF) week 15 July. Liaising with Samoa Cancer Society (SCS) to launch Early warning signs during that visit. Awaiting confirmation of visit by SCS and Samoa NHS.

**Tonga**

* Few referrals recently (one this week)
* Early warning signs being translated.
* Next Pasifika Medical Association meeting (PMA) in Tonga 24-27 September 2013. - website posted on NCCN portal.
* A Tongan paediatric trainee is currently in Whakatane and there is still a possibility of a short attachment at Starship during late 2013/2014.

**PARENT SUPPORT**

* Simon reports no response to emails to Fiji Cancer Society, Walk on Walk Strong (WOWS) and Dr Khalid Mahmood. To resend emails. Simon and Jane planning return “Parent Support” visit to Fiji, June 2013

**PALLIATIVE CARE**

* Janet Mikkelsen currently in Samoa – opportunity arose for her to join team from CMDHB on Palliative Care training. She will be able to provide paediatric perspective. Also plans to link with key personnel (e.g.: Head Nurse, SCS) in Samoa, leading up to visit in July.
* In 2012 WHO updated the Paediatric Palliative Care document. It is evidence based and now titled “*Guidelines on the pharmacological treatment of persisting pain in children with medical illnesses”.* Website link: [*http://whqlibdoc.who.int/publications/2012/9789241548120\_Guidelines.pdf*](http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf)
* Pacific Palliative Care guidelines to be revised/updated.

**Action Items**

* Janet Mikkelsen/Chrissy/Jane to revise/update Pacific Palliative Care guideline.

**EARLY WARNING SIGNS**

* Janet Masina reported on progress with the Samoan document – latest draft posted on NCCN Pacific portal. Feedback requested. SCS opinion to be sought.
* Fiji- Isaiah, using mnemonic “CHILD CANCER” liaising with Fiji and Fijian and Hindi translations completed. Draft to be sent to CCF/Janet Masina, via NCCN portal or Jane Skeen.
* Tonga- translation in progress

**Action Items**

1. Launch Samoan Early Warning Signs in conjunction with an education visit- week 15 July 2013.
2. Roll our Fijian Warning Signs by end 2013.
3. Roll out Tongan Early Warning Signs by Auckland team in conjunction with Tongan colleagues and CCF Tonga at PMA in Tonga- September 2013.
4. Abstract to be submitted to PMA re Early warning signs- closing date July 2103.

**CHARITABLE STATUS FOR WCC NZ**

* Simon has reported that documentation lodged with IRD. Has been informed process complex and protracted.
* Scott reported from Simon’s recent trip to ICCCPO board meeting that WCC rebranded as WCC Global.
* WCCNZ – registered as World Child Cancer Charitable Trust- an independent trust, and organising their 2013 fundraising events in **NZ.**

**PROTOCOL DEVELOPMENT**

**Action Items** (all to be available in draft for discussion by June 30 2013)

1. Scott to workup PI ALL2
2. Peter to look at AML including use of arsenic
3. Rob and Peter to review NHL
4. Jane and Peter to review ALCL
5. Rob to develop Neuroblastoma protocol
6. Chrissy and Isaiah to develop nutrition guideline
7. Peter to review laboratory elements including transport of specimens
8. Chrissy /Jane/Janet Mikkelsen review/update Palliative Care guideline

MEETING CLOSED 1755hrs

**NEXT MEETING**

* Face to face Weds July 10th