



# Peninsula Cerebra Research Unit

## PenCRU Childhood Disability Research

### PenCRU Advisory Group Meeting

Thursday 14<sup>th</sup> June 2012

10.00am – 12.00pm followed by lunch

Venue: Veysey 005

**Present:** Ginny Humphreys, Richard Tomlinson, Bel MacDonald, Antonia East, Claire Lloyd, Chris Morris, Val Shilling, Camilla McHugh, Astrid Janseens, Sarah Bailey

**Apologies:** Tricia Stone, Kim Antonio, Julia Hunt

Welcome and introductions

Points from last meeting:

- KA was going to pass on contact details to CL to follow up
- CL to contact SALT at DHR.

Annual Event

- Concerns have been raised about the steepness of the paths at the Dartmoor Zoo venue.
- MM to ask other students to volunteer to help out on the day, also Andrew
- AE suggested using our posters in the room we will be based in, possibly have Post-it notes available for families to comment or make suggestions
- **Action:** CMc to contact Vinnie to see if he is free again, pass details to GH
- RT knows of another mime if Vinnie is unavailable.
- **Action:** CMc to contact Andrew Gould about possible media coverage; AE will pass on Spotlight contact.

Cerebra Visit

- CM updated on program
- GH and RT to join before 2pm.
- GH mentioned that they commonly direct patients to the website and we may think about other ways to 'advertise' the website to health professionals.

Project Updates

- Possibility of putting the posters together in a booklet or on the website for further dissemination.
- **Action: CMc** to send PDF's to AE and RT (WTE)

#### Newsletter

- When emailing newsletter to GH/health professionals, mention that it is to be passed on.
- General consensus that paper copies do need to be produced and are important for those not on email contact list.
- Cut down on amount of information in the newsletter.
- Consider producing it less often

#### Communication

- Website – update due, possibility of each study having individual page  
**Action: SB** to coordinate
- Twitter – general discussion around the use of Twitter to raise our profile. Considered to be more aimed at professionals than families  
**Action: SB** to set up account
- RT suggested that a PenCRU Facebook page is started in addition to a Twitter account; general agreement from group, BM mentioned families more likely to use Facebook however need to be cautious and look into possibility of closed page  
**Action: SB** to look into having a closed page on Facebook
- Merits of getting involved in BBC Radio Devon programmes discussed, and generally thought that this does reach a wide audience. RT has contacts.

#### Involvement update

##### Update on Children's Faculty

- First meeting has taken place, off to a good start but there are some issues we need to consider particularly around communication.
- Group discussed the possibility that parents would be discouraged from participating in meetings to give the children more chance to answer for themselves.
- It is an option to visit children in schools and other regular young people's settings; they may be more comfortable in a familiar environment.
- BM suggested that Pathfield School in North Devon might have some helpful advice about how to engage children in contributing to decisions

##### Integrating working Groups

- Holding working groups in other locations had been tried with a meeting in Barnstaple – limited in that often a lot of the meeting tends to be dedicated to introduction/catch up.
- It may be better to change the focus of regional groups from a particular issue to a more general discussion.
- RT and GH asked for suggestions for ways we could increase awareness of these working groups among professionals in North Devon and other locations.

- GH to let us know about lead therapists in these areas.

#### INVOLVE conference

- There is another opening for a parent to be involved in presenting. AE expressed an interest.  
**Action: CMc** to send conference website link to AE.
- There are resources for another three parents to come with us to the conference,  
**Action: CMc** will email Family Faculty

#### Seminars and Lectures

- Talks involving practical tips would be more useful than general academic topics; everyone enjoyed Brahm's talk and would like to hear him speak on other topics.
- The possibility of John Shaw coming again to do another talk was discussed, and might be worthwhile if the focus is on what integration means rather than the general ICS service talk.
- AE expressed interest to receive slides from Brahm Norwich talk  
**Action: CMc** ask Cath to send to AE
- GH suggested a talk/ half day seminar on sleep, with the possibility of Bryony Berresford speaking about the SPRU research on this topic. Could also invite commissioners and various local sleep practitioners  
**Action: CM** to follow up

#### Co-chairs for meetings

- The possibility of who should chair meetings was discussed, perhaps a parent. Everyone was happy for CM to continue to chair meetings.

#### Any other business

- GH – Para-Olympic team from Ghana will be coming to Exeter from 20<sup>th</sup> June to mid August. There are opportunities for local children with disabilities to get involved either watching their training sessions, or for the team to visit schools to train. Other opportunities involve the team getting involved with local radio programmes.  
**Action: GH** to send details to CMc.
- Communication in Hospitals – update from CL. Still having difficulties with recruitment of children to interview. It may be possible to recruit from wards – ethics are to be consulted.  
**Action: GH** will pass on details for school nurse at Vbranch House.
- AE raised two possible research questions: effectiveness of hemispherectomy for young children – quality of life and effect on seizures. Prevalence of ASD among other conditions (comorbidity). Was given forms to submit