Brighton and Hove Children’s Hearing Services Working Group (CHSWG)



 [](http://www.google.co.uk/url?url=http://www.thebigidea.co.uk/employer/brighton-and-hove-city-council/&rct=j&frm=1&q=&esrc=s&sa=U&ved=0ahUKEwixi5nq4P_OAhVKBcAKHcRHCsIQwW4IGDAB&usg=AFQjCNEOxE7Qm4gqkjQcPnASo0VdqGiHpA)

**Minutes of meeting held on 18/10/2018**

**Present**-Rob Low - chair (audiology); Alison Davis; Anna Jenkins (parent reps); Janine Blundell (Paediatrics); Ange Ward (community audiology); Sul Regan (SNT); Polly Strauss (NHSP); Helen Murtagh (Healthy Child Team);Vanessa Sharp (community audiology); Stuart Whyte (Southampton CI)

**Apologies**-

**Agenda**-

* Apologies
* Matters arising from previous meeting
* Services and parent reps updates
* NDCS self-audit tool
* AOB

**Updates**:-

**Audiology: Rob Low**

PACC letter received - increased the momentum of talks with commissioners about moving audiology dept. Rob felt that this was the first meaningful interaction. Kathy Felton, commissioner, feels that the trust has not been active enough. New strategic clinical plan - setting priorities. All the building has been allocated - the current issue is moving the current occupiers out. Rob is keen to get audiology in during phase 1 before it is completed. Kathy will go to the chief exec Marian Griffiths. Ali will contact Peter Kyle and Caroline Lucas to suggest that they contact Mariana Griffiths.

JB comment: research has shown that the environment in which parents are seen has an impact on how they think and feel about their treatment - need to establish the patient’s trust.

2 Maternity leaves requiring cover at present: Justine is acting up into lead role. Tanya is doing paed work which has increased her profile as back fill for Laura, plus there has been a new appointment.

Timeline: new strategies released in December, and money identified. ENT consultants are reducing clinical load from 15 to 9 - delay of moving between buildings means ENT almost halving the number of children they see. This is compromising care because they’re not bothering to send for hearing tests. In the new build, will be able to keep pace across the corridor.

VS: suggest internal ‘freedom to speak’ guardian process.

Ali and Anna asked if there was more that they could do - Rob responded that all the plaudits were very helpful, and any complaints had been about the accommodation.

**Parent Representatives: Ali Davis and Anna Jenkins**

website and PACC position statement are progressing.

**Paediatrics: Janine Blundell**

Janine has emailed Katie Fiddler re CMV several times and the Sussex paediatricians have written to agree a pathway for investigating for cCMV and the treatment of babies and children . Current situation is up to 4 weeks a baby can be treated with medication. An older child up to 4years can be recruited on Valgan study. In Brighton only urine is tested not saliva.

We have to remember that even with a CMV the cause of the deafness may be different diagnosis

We have been informed there is a rapid access clinic most weeks - if urine is positive the infant can be seen. We need to know how to access an appointment in the this rapid access clinic. We must have a clear pathway with confirmation of receipt of the referral of and the action.

Polly: Maternity ward: any baby with suspected CMV urine sample is taken (about 7 per week). This was introduced at Trevor Mann a year ago but not always getting clear follow up - who does the sample go to? Who will act on it? Are parents being told and consenting?

The team recognise cCMV can result in later onset unilateral or bilateral SNHL

We therefore need a clear pathway / e.g. if a baby passes the screen then tests positive for CMV can an email alert be sent?

Janine : We discussed older children who have been picked up to have had cCMV from newborn blood spot. Question asked to Katie Fidler - do we refer to her for treatment to be considered or can we only recruit on Toddler Valgan study?

Concerns re later: Parents do not want be on the trial in case they are on placebo arm.

Reason Katie may not treat:

* Katie is concerned re bone marrow suppression but the vast majority have no issues.
* No current published large evidence that treatment will stop progression ( initial studies suggests it does)

Of note: CMV saliva test cannot be taken at least 90mins-2hours after feeding because CMV often in breast milk

1 in 200 babies have CMV. Only 10% symptomatic ( unwell) and not all have hearing loss. Of non-symptomatic / well infants estimated 25% will have hearing loss.

Rob: Janine, Rob and Polly will put together a pathway. To achieve this must meet with Katie Fiddler ASAP . To be on the agenda for the Pan Sussex meeting 14th November.

**Health Visitors: Helen Murtagh**

catching children that transfer into the area: HVs make sure that they know of children new to the area very quickly. Polly: children from overseas can be screened up to 3 months but what happens after that? Polly can send a letter to HV to be sure they’re aware of them - or could send targeted referral to community audiology and copy in HV and GP. Vanessa: it would be good to have a pathway with this so that everyone is clear of the process. Rob: also include eligibility to NHS - usually flags up on system 1 so need to include this in the pathway.

**NHSP: Polly Strauss** no further issues

**Southampton CI: Stuart Whyte**

Stuart introduced himself as also in the UIC radio aid working group (who authorised the NDCS quality standards). The group have put pressure on the move towards integrated FM into hearing aids which is currently being pushed forward. Also exploring the possibility of FMs being covered for insurance by the local authority.

In his TOD role at Southampton, covers a large area and is aware of the impact on families. Trying to set up satellite clinics eg at Eastbourne and Hamilton lodge. Weekly clinic now at the elizabeth foundation - has an audiology booth, medical room, rehab room. Rob: can local professionals do the long term managing? This feels like an achievable step for local audiologists. Would welcome them to remain on the clinical list - eg. To go to implant centre but then be able to be monitored locally.

New guidelines on criteria for referral - now can take an average: if the average is 90 or above a referral can be accepted.

New NICE guidelines means more CI available to more children. Currently 11 children being assessed in Sussex.

SOTON online: what a CI is, device choice, Neptune and Naida, Sonnet from MEDEL

Coffee morning at Elizabeth foundation for parents.

**Community audiology: Vanessa Sharp:** redevelopment of Brighton General hospital going ahead. Angela is retiring.

**Sensory Needs Team: Sul Regan:**

Pan sussex training in November - 3 teams sharing training and resources. Have invited ‘Speaksee’ from the Netherlands to demo voice to type system that we want to trial with an MSI child at secondary school. May be of interest to SALT katy liriano and to Vanessa’s team - once confirmed sul will check size of room and if appropriate send out invites.

NDCS Self-audit tool: ran out of time to discuss this today. Team leaders to complete prior to next meeting.

**AOB**- none

**Next meeting scheduled for February 14th 2019 at 10am**

**Hollingbury Learning Centre, County Oak Avenue, Brighton, BN1 8DJ**