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## HYPNET Meeting - 17<sup>th</sup> January 2011

Evalina Children's Hospital, kindly sponsored by Janssen

### PSYCHOLOGY STUDIES

Michael Evangeli

Michael is recruiting for a qualitative study of perinatally infected young adults: 6/8 recruited between 18 -24 years.

Two issues raised so far:

1. Considerations of HIV status of partners – disclosure or not
2. Issues around condom use or not.

Come back to team to discuss which points are more salient.

Need to learn about emotional issues in relationships.

Looking towards new projects 2012/13 -Michael and team organises everything. You can get involved without taking up your time. It comes with funding so no funding requirement. Ideas very welcome and please email michael evangeli

[Michael.Evangeli@rhul.ac.uk](mailto:Michael.Evangeli@rhul.ac.uk)

### AALPHI Update

Update sent by Ali Judd – study still going through ethics. Band 7 nurses being recruited - early March. Anyone interested please email her Ali Judd Judd [AJ@ctu.mrc.ac.uk](mailto:AJ@ctu.mrc.ac.uk) .

### HYPNET AUDITS

Katia Prime: Audits for 2011 below. Audits for 2012 and beyond welcome.

Emails from paed units finding out the follow on units for transitioned pts:

GUM Dr's to be made aware who are treating adolescents– send to

[caroline.foster@imperial.nhs.uk](mailto:caroline.foster@imperial.nhs.uk) .

Audit leads to be awarded certificates for their CPD, on-going training etc.

**Action: Esse has agreed for her child to design certificate.**

Daniella Chilton [Daniella.Chilton@gstt.nhs.uk](mailto:Daniella.Chilton@gstt.nhs.uk) – CERVICAL SMEAR AUDIT. Form designed for collating of information.

**Action: Daniella - Add further questions determining route of transmission ie perinatal and evidence for, age 16-25, Denominator data, how many women have not had smears? HPV vaccination? Register with audit centre at St Thomas's**

Caroline Foster [caroline.foster@imperial.nhs.uk](mailto:caroline.foster@imperial.nhs.uk) –MORTALITY AUDIT:

Handful of pts. Pat and Ali have been emailed for CHIPS data and happy to participate.

Detailed form regarding pt treatment history.

**Action CF: data on last seen /appt on form to be added.**

**Adherence – more information to be added on form by CF going into depth of why non-adherent. Further family history. CF Recirculate**

Alternative could be a detailed death summary. This could be qualitative study because numbers are low – SPR from Mortimer Market will be asked if interested to help. Plan to present both audits BHIVA 2012

## **ADHERENCE GROUP**

Susan McDonald [Susan.McDonald@imperial.nhs.uk](mailto:Susan.McDonald@imperial.nhs.uk) and group have submitted abstract to BHIVA 2011. Full version on web – summary: 138 pts on HAART age 12-24 questionnaire – 60% female, 65% born in UK, 41% VL undetectable, Family support is the most important factor

Barriers to adherence: secrecy within family and friends, fear of disclosure.

**Action: Will be written up as short report by SM and CF to liaise with Debbie Levitt re completion of guidelines.**

## **CONSULTATIONS**

BHIVA-BASHH Criminalisation of HIV Document for consultation – forwarded by CHIVA for response on <18 yrs section.

No one previously aware of this document.

Lisa Power and Yusef Azwad involved and liased through NCB consultation on previous criminalisation document and is in line with this guidance.

Short time line for document:

**Action: CF to send out HYPNet response and all others interested to comment via BHIVA web. (done)**

Testing of those children who are 18 and over and parents are HIV positive but decline to inform offspring

Guidance requested from BHIVA and CHIVA by group at Imperial – response awaited

## **GOOD PRACTICE IN ADOLESCENT CARE**

Good practice to be shared across different units – Led by Katia Prime

[Katia.Prime@stgeorges.nhs.uk](mailto:Katia.Prime@stgeorges.nhs.uk) and [Eva.Jungmann@Camdenpct.nhs.uk](mailto:Eva.Jungmann@Camdenpct.nhs.uk)

Proformas established in other centres to be amalgamated into a HYPNet set available on the web – particularly important for smaller centres outside london and to prevent “re-inventing the wheel”

**Action: Liz.hamlyn@nhs.net is happy to lead on this project and will contact centres but also ALL to email existing proformas.**

Rebecca Hope [rebeccahope@doctors.org.uk](mailto:rebeccahope@doctors.org.uk) is going to lead a group setting up an A-Z of young persons services accessed via the HYPNet web

**Action: RH to develop proforma and liaise with David Morgan re the web practicalities**  
[morganiser@hotmail.co.uk](mailto:morganiser@hotmail.co.uk)

NCB - Emily Hamlin is leading a Transition project particularly looking at services outside London. **ALL- To keep up-dated, sign up for e-bulletin.**

## GUIDELINES

Sexual Health: Only awaiting BHIVA approval -sent to Sarah Fidler but she is not on BHIVA Guidelines committee- SF will read + give recommendation.

## PEER SUPPORT

Body and Soul and St Georges- Trial for 1 year at St George's.

2 peer mentors from other services attend clinics at St George's once a month. Pro-forma is kept of what is discussed – categories not detailed.. Hoped further funding maybe secured from London Consortium if shown to be beneficial at evaluation. Daniella Chiltern from St Thomas's is in discussion with Body and Soul also. Funding of £5K secured through Janssen scholarship programme looking at transition from adolescence to adulthood . Cost £3,500 per year, but it is shoe string.

## CHIVA AFRICA

Any volunteers for a week on the adolescent program -good background in sexual health and HIV required. EJ – found it very rewarding.

South Africa House 3<sup>rd</sup> Feb update day. EJ – found it very rewarding.

See CHIVA Africa website if anyone is interested or email CF.

## HYPNET Committee & Finances

Committee Chair – Caroline will have completed her 3 years in June. After the next meeting nominations for chair and voting as previously felt to be best system. Outgoing chair to provide 6 months handover period if possible. **Action: Please let Caroline know if you are interested**

To avoid all changing at same time Committee changes January 2012.

HYPNET finances - balance £3455 – however majority was given specifically for patient leaflets. £1500 donated specifically for web upkeep. BHIVA registration provide for those who lead and present audits. Fundraising for HYPNET – money can be donated via CHIVA as they hold they account.

HYPNET Web upkeep done by David Morgan - £200 per quarter - anyone prepared to help with submitting to the website/information as the committee web member?

## AOB:

Katia Prime - Princes Trust work experience for disadvantaged youths 18 +

CHIVA newsletter – update from HYPNET to CHIVA required for newsletter. **Due by the end of this week – CF to do (done)**

A 5<sup>th</sup> HYPNET “prevention leaflet” patient leaflet – HIV transmission facts and how to use a condom for uninfected young people, which was made for World Aids Day 2010 by a young person on the youth committee and kindly funded 2000 copies by Janssen distributed with student news letter.

**Next meeting: Wednesday 25<sup>th</sup> May at Body and Soul.**