



HIV Young person's Network Minutes from 24.06.09 The Hilton Metropole.

1. Dr Ali Judd opened the meeting and discussed the AALPHI. Aim to establish new cohort of 400 perinatally HIV-infected young people aged ≥ 14 and follow through transition; compare to 300 -ve sibling controls. Investigate the impact of life-long HIV and long-term ART on a number of areas: disease progression; ART-related toxicities & resistance; growth and puberty; neuro-developmental/ psychological function; sexual & reproductive health; quality of life. Use cohort as sampling frame for separately funded sub-studies. This proposal was rejected by the Wellcome foundation, but other members discussed where they may be able to get part funding.

Also discussed was the CHIPS long term follow up. Is this surveillance- if so it is non consented? Could adolescent clinics report to CHIPS. Dr Lyall thought this data is very helpful for Sub Saharan Africa. The French and US have similar data and it would be nice to pool all data and then it would be more meaningful. UK quite unique in coverage of paediatric HIV is widespread and not just in big centres so a big effort is needed to collect data.

2. Dr Katia Prime presented on Capacity and Fraser competence. She showed a consent sheet that is used at St George's. The first part is to assess the competency of an <16yrs, to check the individual understands the nature, the purpose, risks associated with intervention and also the risk if no intervention. Should this be done at every visit if unaccompanied <16yrs. The second part was assessment of Fraser competence, contraception, STI, physical exam and treatment. Main aim is to ascertain that the patient understands advice, that the patient is encouraged to inform the parent if providing sex or contraceptive advice but always must be in the best interest of the patient.

Action: Katia to send e copy of form to Caroline F and she will e mail all members.

These core principles could apply to other therapies e.g. epilepsy, diabetes.....

3. Julia Kenny presented on planned pregnancy audit. Forms circulated- pregnant young women with perinatally acquired HIV. NSHPC data- 11 pregnancies to live births- small numbers so far. Pat Tookey raised questions on clarity of who is perinatally infected, if diagnosed as a child it is not a problem, but those diagnosed in teenage years or in teenage pregnancy and even where their mother died of HIV, this does not mean perinatal transmission.

Action: Julia to liaise with Pat Tookey re final forms returned to Caroline for circulation with covering letter by early/mid July.

4. Maria Phelan discussed criminalisation of HIV. Since 2001 16 cases have gone to court, 11 convictions and includes one young person. Difficult area as U16 are vulnerable. CPS has been asked for a meeting but declined initially but further representation by NCB, NAT, THT continuing. Questions as to where is the duty of care particularly for SW and looked after children. There are NAT guidelines for adults. CHIVA meeting (open to all) at the MRC building 222 Euston Rd on Monday 6th July, where cases will be discussed.
5. Debbie Levitt spoke on adherence guidelines. There is a questionnaire for 12 to 24 yr olds, hope to have all data collected by Christmas. Envisage analysis of data by Feb and so handbook may be available late spring. There will also be 9 workshops over the summer which might show peer support.
6. Caroline Foster talked about HPV vaccine. Gardasil is the preferred drug, 15% reduction by Drug Company. Guidance sent to BHIVA and to BASHH for consultation. The timescale depends on commissioners who have now responded saying: that this would need to be “service development” as and such would need to demonstrate cost effectiveness. However this will be extremely difficult as this is an emerging population so longterm cancer/STI data not available and the first vaccine safety and efficacy data reports in September in this population but will not demonstrate any \$. Action: Caroline will discuss further with Paddy - CHIVA Chair.
7. There will also be Adolescent HIV treatment guidelines as requested from BHIVA. If there are any other things that should be added let Caroline know.
A discussion followed on smears and colposcopy- there was no consensus.
Action; Dr Nwokollo agreed to go through the recent data on outcomes.
8. Hermione Lyall raised point re Fertility in perinatally infected young men is an area with no data.
Action: Steve Welch to liaise with adult colleagues in Birmingham re study ethics/feasibility.
9. Patient leaflets were discussed and credit card type info is popular with adolescents but very expensive to produce although some funding is secured. Action: Roger Peabody from NAM will liaise with Katia and Caroline re costs.
10. Website discussed and agreed separate HYPNet web – simple with a page on CHIVA to be discussed. Magda Conway has very kindly offered to take on development, some funding secured. Domain is hypnet.org.uk
11. AOB HYPNET account needs to be set up. Action; Caroline to ask Colin Ball the best way to do it and whether it could be done through CHIVA.

12. Next Meeting 28th Sept, at Body and Soul 6pm for 6.30pm start