

Minutes of the VI GenomEUtwin steering group meeting, Rotterdam, The Netherlands October 7th, 2003 Notes taken by Markus Perola (MP)

Present:

Aarno Palotie (AP)
Alun Evans (AE)
Ann-Christine Syvänen (AS)
Antonia Stazi (AS)
Jaakko Kaprio (JK)
Jan-Eric Litton (JL)
Jennifer Harris (JH)
Kaare Christensen (KC)
Kirsten Ohm Kyvik (KOK)
Kari Kuulasmaa (KK)
Leena Peltonen (LP)
Nancy Pedersen (NP)
Nick Martin (NM)
Tim Spector (TS)

-LP addressed the plans of the next year and future actions of GenomEUtwin (on the website).

Yesterday's SAB meeting was discussed. General feeling was satisfied. Special attention was paid on the suggestions for educational plans. SAB recommended for GenomEUtwin that we should concentrate more on workshops and scientist meetings on specific study-specific issues, however JH pointed out that CoGene's SAB had recommended quite the opposite for that project.

Action item 1: JH initiates a discussion on the educational aspects of Genomeutwin when SAB comments are received.

-CHD/Stroke phenotypes were discussed as targets for genome analyses. It was commonly agreed that there probably is not enough concordant pairs for any reasonable analysis, however it was also clearly seen that there is a need to analyze this issue specifically as soon as possible.

Action item 2: Each centre provides a list of concordant sibs for CHD/Stroke to Kaare for inventory purposes and power estimations.

-The discussion turned into other phenotypes. It was seen, that we still need more detailed info on the data available.

Action item 3: Each phenotype group dedicates a person to collect the available data on each phenotype, as well as the number of discordant/concordant pairs collected for each phenotype. Specifically, genome-wide linkage analyses of available raw genotype data of BMI and stature were accredited under the direction of MP.

-It was noted, that other biological samples than DNA should be pursued whenever possible.

Action item 4: Serum/RNA/cells should be collected when sampling whenever possible.

Action item 5: Each centre delivers 30-60 trios for SNP genotyping with ample amounts of DNA to screen for haplotype variation across the populations. These need not be twins, just father-mother-offspring trios with 25-50 mikrograms of DNA that can be used. ACS coordinates this effort.

-The situation of the statistical core was discussed. The agreed movement of the funds from Leiden to Odense and Amsterdam had not yet happened but was in progress. However, the continuation of that was an open question and needed clarification in the next steering group meeting.

Action Item 6: KC and DB discuss the practicalities with HH about the funding issues for statistical analyses.

VII GSG meeting will be held in Paris January 13.-15., 2004.

VIII GSG meeting was agreed to be held in conjunction with the genetic epidemiology workshop in Cambridge, 4-7. April. GSG meeting would be on the 7th.

(Markus's note: this has changed since that)

IX GSG meeting in 2004 will be held in conjunction with the Odense twin meeting July 5th.

LP, JK and AP left the meeting.

AE and KK explained the major differences in the ethical and IP aspects or the MORGAM study when compared to Genomeutwin.

-the genotype data will be sent back to Morgam Participating Centres on request. It is emphasized that if any genotype data results indicate that patient contact is necessary, the genotyping must be redone from a fresh sample. This is timely for the Finnish Finrisk cohort, where the ethical committee will be consulted for advice on this, specifically for the FV APC mutation.

IP issues were discussed. MORGAM has taken a stand that can be found from:

<http://www.ktl.fi/morgam/internal/manual/description/commercial.htm>

In Genomeutwin, it was doubted according to previous experience whether any findings would be worth patenting. However, it was decided that if any such patentable product is foreseen, the PI (LP) should be immediately contacted to discuss the working plan. In general, the product should be protected at least for a year after this consultation. A specific consortium agreement was not seen necessary. However, it was noted that according to EU rules, in a case that no such consortium agreement is in effect, all participants own the results together.

Meeting was adjourned.

