NIPT and Prenatal Testing in Belgium

Practice and Reflections

Dr. Kristien Hens
Maastricht University

Prenatal Testing in Belgium

- Now:
  - First Semester Combination Test offered to all pregnant women, fully reimbursed (80% uptake)
  - Invasive Prenatal Diagnosis also reimbursed (offered @risk of 1/300)
  - NIPT offered on an ad hoc basis (advanced maternal age, previous child with T21, result of CT, anxiety…), 460 Euro
  - Termination of pregnancy for ‘severe medical reasons’ allowed till late in pregnancy

Prenatal Testing in Belgium

- Genetic Testing done at one of the eight (licensed) centres of human genetics
  - 7 linked to universities: ULB, VUB, UCL, ULG, UA, RUG, KUL
  - One independent: IPG @Charlerloi
- Microarray (array-CGH) used for invasive
- NIPT: analysis now done at some centres, rest will follow soon

NIPT: Superior Health Council of Belgium

- *Aim*:
  Position of NIPT in the Belgian healthcare system
- *Focus*: Trisomy-21
- *Conclusion*:
  NIPT offers a significant advantage over current screening techniques
  From technical point of view best to replace current first line screens
- Need for pilot, accurate information, counceling etc..

NIPT: Belgian Health Care Knowledge Centre

- *Aim*:
  To investigate health economic aspects
- *Focus*: Trisomy-21
- *Method*: Literature study, simulation
  - !! Lifetime cost of Down, QALY.. not taken into account
- *Conclusion*:
  From cost effectiveness, best as a second line screening

Press Release Down Syndrome Flanders

- Endorsement
- But: against single sided information
  - Informed decision making should also include talking to parents of people with Down syndrome
  - Also: NIPT as a possibility to prepare for birth of Down syndrome child

Bioethics: The reality of NIPT

- Bioethicists should…
  - Be aware of the possibilities of the screening
    - Trisomy-21, not monogenics
  - At 12 weeks due to fetal fraction
    - Reality of the pregnant woman
    - Need for empirical studies
  - Possibility to do NIPT as a way to prepare for a disabled child rather than to terminate a pregnancy
    - Not necessarily a next step into eliminating Down syndrome
  - NIPT as an alternative to PGD/PGS???
    - IMHO not realistic?
  - Also chromosomal abnormalities raise ethical questions!

The Ethics of Chromosomal Abnormalities

- Trisomy-21
  - Based on reproductive autonomy, but…

    Who gives correct information?
  - Disability Rights Critique
    - Expressivist argument
    - Idea of ‘being prepared’ becomes more important with NIPT, should be investigated and equally important than termination route
- Trisomy-13, trisomy-18
  - Nobrainer, but…
  - Responsibility of the professional?

The Ethics of Chromosomal Abnormalities

- Sex Chromosome Abnormalities
  - Description of Phenotype biased
  - Reproductive autonomy?
  - Parent's right to know versus child's right to chromosomal privacy?
    - E.g. Klinefelter and infertility
    - E.g XYY and Pygmalion effect
- Submicroscopic chromosomal abnormalities
  - E.g 22q11 deletions
  - Others that are associated with autism etc…
  - Parental right to know versus uncertaintly of information
  - Sheds new light on trisomy-21 screening: Do we screen for what is worse or what is technically feasible?

The Ethics of Chromosomal Abnormalities

- We do not need SF scenarios of Designer Babies or whole genome scans: also at the level of the chromosomes there is a host of relevant questions
- NIPT makes this discussion even more pertinent than PGS/PGD.
- What do we tell future parents? What do we check for? Who decides?

Mail me!
k.hens@maastrichtuniversity.nl