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# Genetics and Human Behavior

IV annual Swedish Symposium on Biomedicine, Ethics and Society

When Does Genetics Play a Role in Understanding Human Behavior?

Sandhamn Hotell & Konferens, May 27-28, 2002

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## **What can we learn from participants of ABIS, a research screening for Type 1 diabetes?**

**Background** The prospects of prevention in case of development of Type 1 diabetes (IDDM) is of high interest at present: we are witnessing an increase in incidence (in the ABIS region for those < 15 years of age at present close to 50/100 000/year), but research is troubled by imprecise markers, the complexity of the interaction between multiple genes and gene-environment and the potential ethical and psychological consequences.

**Setting** ABIS (All Babies In Southeast Sweden), is designed as a longitudinal and geographically located research screening for Type 1 diabetes in an unselected birth cohort (October 1997-October 1999, present outcome 78%, n=17000). The children are actively followed up to the age of 6, with blood samples, a one-year diary, intermediate questionnaires and other biological samples (stool, urine, tooth, saliva). A general follow-up to 20 years of age are planned at the moment.

**Methods** As part of the main study two doctoral thesis are incorporated, exploring and analysing bioethical and psychological (psychosocial) issues. The data will originate from, 1), the main study's questionnaires (at birth, 1, 2-3 and 5-6 years of age) with bioethical and psychosocial questions incorporated, 2), structured to explorative interviews with participating and non-participating families and staff involved in each process from Maternity Welfare (MVC) to Children Welfare centre (BVC), 3), a designed bioethical questionnaire exploring areas of bioethical interest: information, informed consent, proxy, results, restrictions and confidentiality and prevention/intervention and, 4), a psychological in-depth interviews with mothers concerning their own representation of early childhood relationships. Main instruments used to tap psychosocial issues are demographic background variables (e.g. parental age, education, employment situation, marital status); social support; experienced confidence; parental satisfaction (3 questions from SP; Crnic & Greenberg, 1990); parenting stress (SPSQ; Östberg, Hagekull & Wettergren, 1997); maternal attachment status using both a self-report instrument and an in-depth interview.

**Results** Participating mothers have a very positive attitude to ABIS, but their informed consent sometimes seems to be based on incomplete understanding. Most participants do not get worried but calmer by participation. Psychoimmunology may be one pathway/trigger mechanism to development of diabetes.- Future analyses may reveal connections between genetics and behaviour of importance for the immune system.



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