

## Jahrestagung 2004

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# European Society of Human Genetics Deutsche Gesellschaft für Humangenetik

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### Psychosocial aspects of Predictive testing

The increasing knowledge about the human genome has resulted in the availability of a steadily increasing number of predictive genetic tests. Predictive genetic tests give asymptomatic persons, who are at increased risk for a specific hereditary disease running in the family, the possibility to know with certainty or with a high probability whether they will become affected later in life. When predictive testing for Huntington's disease became available in the late 1980's, it was a milestone in the history of genetics, although there were fears about how individuals would cope with the results of tests. Today this possibility exists for several neurogenetic diseases, hereditary cancers and hereditary heart diseases. At-risk persons can choose whether they want to know or not. In some situations there are preventive measures to early detect, to postpone or to prevent the disease, in other situations this is not possible. The complexity of predictive testing for late onset diseases necessitates a careful multidisciplinary approach tailored to the needs of the testees. Moreover, follow-up studies are of the utmost importance to evaluate the long-term impact of predictive testing on the tested person and his/her family. EMPAG-conferences have always paid attention to **psychosocial factors playing a part in the uptake for predictive testing and to the evaluation of the psychosocial impact of the test result**. During the meeting in Munich new data will be presented during a plenary EMPAG-session. For **Huntington's disease** short-term paradoxical reactions and long-term psychological and social adjustments in persons with a favourable test result will be illustrated based on a large number of interviews. Another presentation will deal with the impact of the test result on the perceived quality of the relationship with the partner in the five-year period after testing and on the perceived changes in the relationship. The psychosocial impact of predictive testing for **hereditary breast and ovarian cancer** will be discussed in another presentation based on a multi-centre study with a three-year follow-up period. Predictive testing for **hereditary melanoma** will receive attention in two presentations: the first focuses on the reasons for reluctance to genetic testing and the second on psychosocial issues for families at high risk. In the context of hereditary heart disease the clinical indications and an ethical analysis of the reasons for and against predictive testing for **hypertrophic cardiomyopathy** in children will be presented. Overall this session on psychosocial aspects of predictive testing will elicit interesting discussions.

### Contact persons

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