GEN DG – Experience and consequences for life insurance companies in Germany

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Agenda

1	Introduction
2	Legal aspects (GEN DG)
3	Underwritíng procedure
4	Experience and results

Introduction

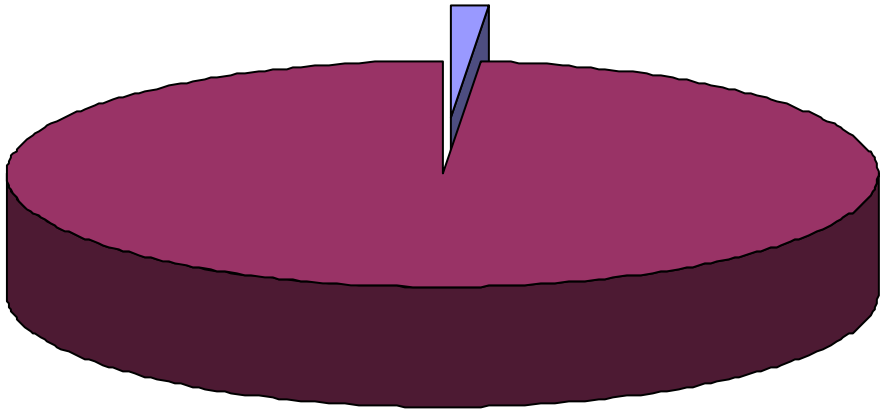
- Since 2010 underwriters in Germany have to respect the GEN DG in their daily work
- At the beginning there was great uncertainty regarding the diffferent aspects of the law
- After a period of familiarization the underwriters became more and more used to genetic tests
- Even after the training period it‘s somestimes still difficult to distinguish and detect genetic information in medical reports

Introduction - Different genetic tests

Monogenetic diseases 1%

approx. 6,000 diseases detectable by genetic testing

Cystic fibrosis
Factor V Leiden
BRCA1 und BRCA2
hemochromatosis
Chorea Huntington disease
Duchenne's Dystrophie
Charcot-Marie-Tooth (HMSN)



"Widespread diseases"
99% not detectable with genetic tests

Predictive and diagnostic tests

Diagnostic test	Predictive test
After having diagnosed a disease that may be genetically associated. (e.g. Factor V Leiden after thrombosis)	Genetic test is performed to predict a disease before clinical symptoms occur (e.g. haemochromatosis)

Introduction – Genetic tests prove

Thrombosis
Thrombophilie
Factor 5 and other

Mental Retardation
Trisomie 21
Chromosome tests

Iron Overload
Hemochromatosis HFE-Genetic test

Pneumonia
Cystic fibrosis > CFTR-Genetic test

Fainting symptoms
> long QT-Syndrom
> KCNQ11

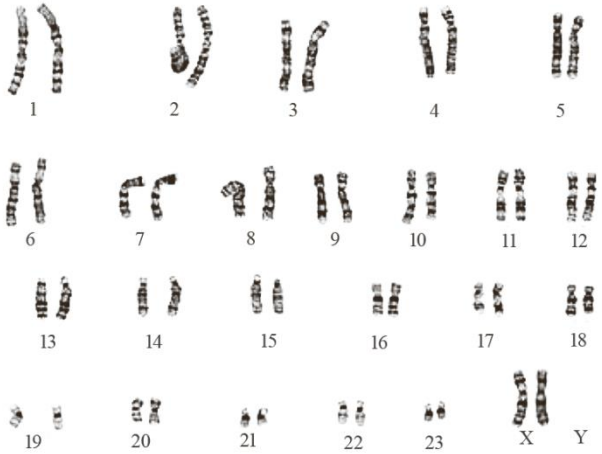
Breast Cancer
BRCA1/2, HER2

Colon Cancer
HNPCC / FAP

Stumble symptoms
Charcot-Marie-Tooth
PMP22-Genetic test

Different kind of tests

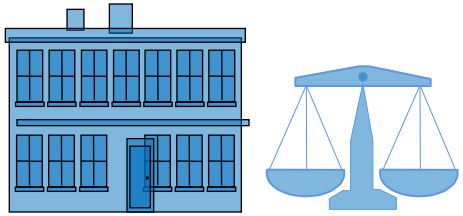
- Cytogenetic test (number and structure of chromosomes)
- Molecular genetic test (RNA, DNA)
- Analysis of genproducts (Proteins)



Predictive character of genetic tests

1960

Applicant with Chorea Huntington in his familiy



Private insurance company

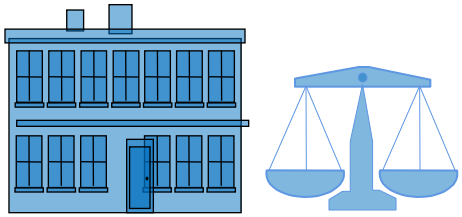
50 % „CH positive“

50 % „CH negative“

higher premium

2009

Applicant with Chorea Huntington in his family



Private insurance company

Antiselection

85 % (?) „CH positive“

15 % (?) „CH negative“

Higher premium still sufficient?

Predictive test – importance

Women with a genetic mutation of one of two genes, BRCA1 or BRCA2, have a higher risk:

- For breast cancer (50-80%)
- For breast cancer on the contralateral side (60%)
- For ovarian cancer (40-60%)

Legal Aspects (§ 18 GEN DG)

Genetic test and analysis in connection with an insurance contract

For insurance companies it is forbidden:

(1) To demand the performance of genetic tests or analysis or

(2) To ask for the results or data of a genetic test or to **accept** such tests.

but

Pre -existing **diseases** have to be declared
(§§ 19 to 22 and 47)

Legal Aspects (§ 18 GEN DG)

- **Prohibition of notification**

  The information of a performed test is forbidden
- **Prohibition of acceptance**

- **Prohibition of application**

  At no time is the use of the result of a genetic test allowed
- **Prohibition of execution (verwendung)**

Even if a test has been performed and the results are known they can not be used

Acceptance and handling of genetic tests

- Important isn‘t the **reception** of the test at the insurance company but the intention to use the genetic test
- Predictive test results have to be deleted from the electronic system
- Important information has to taken out
- The use of diagnostic test is allowed if the disease is known

Underwriting procedure- where genetic tests can be found?

- Accidently in a normal application
- In case of a pre enquiry
- Sometimes genetic tests are difficult to detect in medical reports

Patient(in) | Geb.-Datum .1980/M | Eingang/Probennummer 17.09.02/

SSW/ZT: | Station:

	Ergebnis	Einheit	Richtwerte
Protein C	117	%	70-140
Protein S, freies (Aktivität)	129	%	65-145
Faktor V Leiden-Mutation	positiv		negativ

Der Patient ist heterozygoter(!) Merkmalsträger bezüglich der Faktor V-Genmutation.

Beurteilung:
Eine heterozygote Genmutation im Faktor V-Gen ist mit einem 5-10fach erhöhten Thromboserisiko verbunden.
Bei Einnahme oraler Kontrazeptiva oder Medikamenten zur postmenopausalen Hormonsubstitution ergibt sich bei heterozygoten Merkmalsträgerinnen ein ca. 30fach erhöhtes Thromboserisiko.
CAVE: Heterozygote Merkmalsträger sind potentielle Überträger der Mutation.

Exceptions – what‘s allowed in the underwriting procedure?

Life

Sum	Predictive	Diagnostic
< 300.000 EUR	Not allowed	allowed
> 300.000 EUR	allowed	allowed

BU

Sum	Predictive	Diagnostic
< 30.000 EUR	Not allowed	allowed
> 30.000 EUR	allowed	allowed

Attention

- The analysis of genproduct (beside DNA, RNA and chromosomes) is also forbidden by law
- **BUT:** Analysis of cholesterol is based on **gen**products !
- Therefore there is an agreement that the analysis of cholesterol in family history is not allowed if the purpose is to detect the genetic pattern which is responsible for the disease.
- Assessment of cholesterol for coronary heart disease is a gen product analysis but it is not the genetic pattern that is important and therefore it‘s not a genetic test in the sense of GENDG

- Family history is not definitely regulated by the GEN DG

Underwriting procedure

- In uncertain cases an additional questionnaire is necessary
- Genetic information can‘t be the reason for higher premium (only the existing disease)
- Predictive tests have to be removed from electronic database
- Genetic tests which were sent accidently to the assurance company are stored physically in a treasury independent of the lump sum

General Experience

- Between January 2010 and December 2012 all stored genetic tests were evaluated
- After passing the law the underwriting team has been trained
- After a learning period genetic tests were found easily by underwriters
- The biggest challenge for underwriters was to distinguish predicitive from diagnostic tests at the beginning
- The most common genetically determined disease which was found, was thrombosis in women with an anticoagulation deficit (Factor V Leiden, AT III deficiency, APC resistance, MTHFR Mutation, Protein C deficiency)

Results

- 46 tests were stored
- Most of them were diagnostic tests
- Only a small number (4) were predictive tests
- Factor V Leiden and other tests for coagulation disorders were the most often detected diseases
- None of the predictive tests received were for policies exceeding the sum of 300,000 EUR for life insurance
- The second most common disease was hemochromatosis. One of these tests was predictive
- The predictive hemochromatosis test doesn‘t have any negative implication for the insurance company (therapy by bleeding)

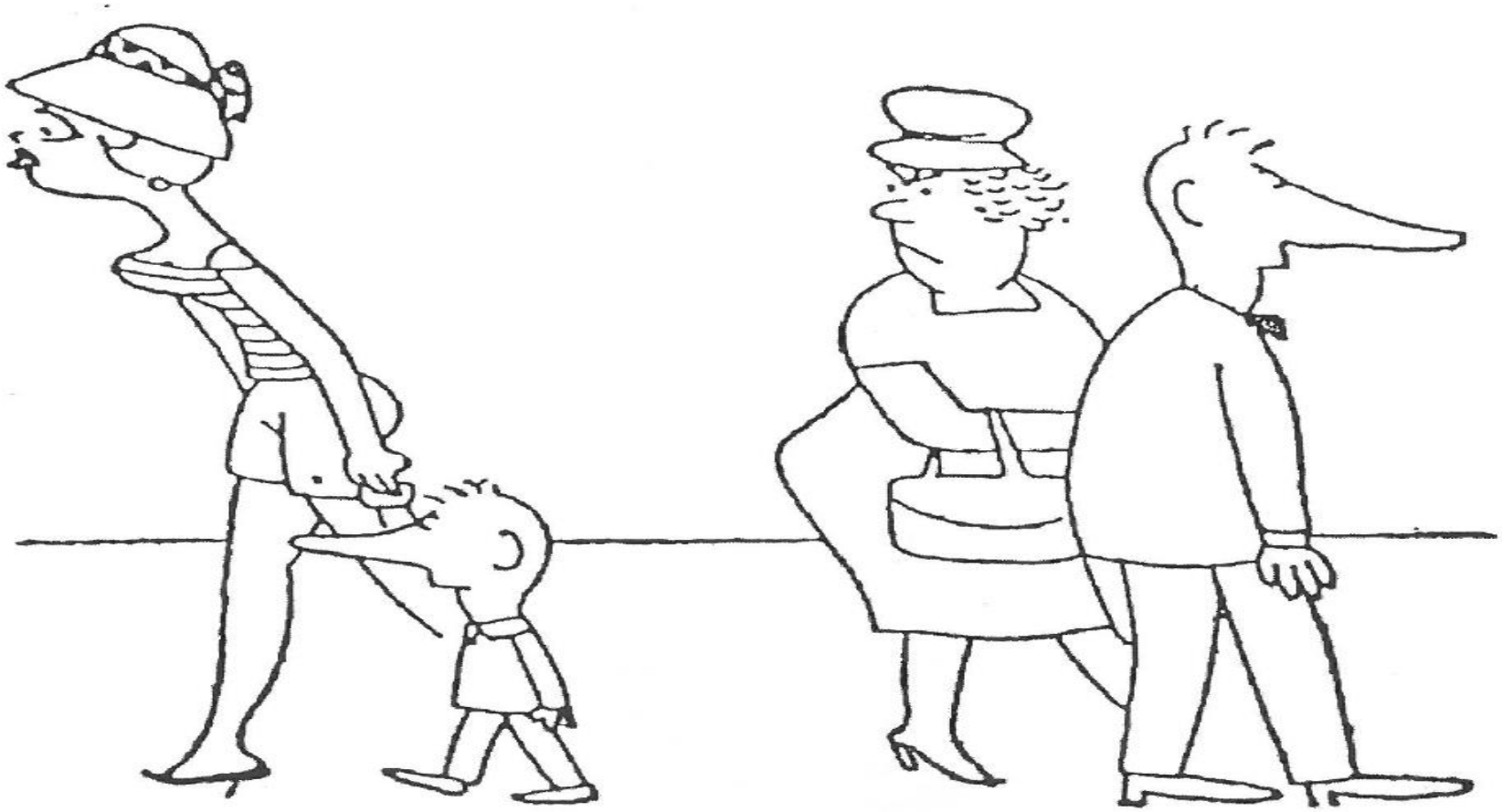
Take home message

- Genetic tests are common in daily underwriting procedure
- After a period of training most of the genetic tests are identified today by the underwriters
- Sometimes it still remains difficult to recognize and evaluate the test (predictive or diagnostic)
- Mostly diagnostic tests were observed in people with coagulation problems
- Possible antiselection is not common
- Finally, in the long run, premiums will rise (especially if genetic tests become more common)
- All assurance underwriters have to be trained on this topic
- Heterozygous genetic properties are less important than homozygous

Take home message

- The one predictive test will lead to a claim which demonstrates the problem for the life insurance companies
- Antiselection is greater for the disability insurance.
- Only a few monogenetic diseases which are detected by a predictive test are terminal
- For the time being, the cost of disability and life insurances won‘t be raised by the antiselection
- The biggest challenge for the insurance companies could be when a client asks different assurance companies for a disability cover below the threshold of 30, 000 EUR

Thankyou for your attention



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