

Centrum Medische Genetica

Erkenningsnummer 8 11990-94-996

Prins Boudewijnlaan 43/6 • B-2650 Edegem • Tel: +32 (0)3 275 97 74

Fax: +32 (0)3 275 97 23 • www.genetica-antwerpen.be



Concerning: genetic testing using exome or genome sequencing to detect genetic defects (mutations).

INFORMED CONSENT

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| Į | <u>I was ex</u> | plained | l and l | <u>l have</u> | unders | <u>tood</u> | <u>that</u> | į |
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| 1. | Extended genetic testing is suggested for the cause of a genetic disorder. | | | | | | |
|------|---|--|--|--|--|--|--|
| | namely(condition) | | | | | | |
| | in myself (name) date of birth | | | | | | |
| 2. | To this purpose, a large number or all genes will be examined. | | | | | | |
| 3. | These data will be analysed to allow the cause of the condition to be identified. | | | | | | |
| 4. | The physician will discuss the results of this analysis with me. Results of any follow-up analysis that are of clinical significance wil also be discussed with me. | | | | | | |
| 5. | It is possible that this test will not explain my/my child's condition in the short term. As knowledge about genetic conditions is evolving, I may contact my physician again in the future to ask if there are any new insights that could influence the results of this analysis. | | | | | | |
| 6. | I will be informed if by chance a serious hereditary disease is found for which medical treatment and/or prevention is possible or it am a carrier of a disease with at least 25% risk for offspring. | | | | | | |
| 7. | I will not be informed if by chance a serious hereditary disease is discovered for which no medical treatment and/or prevention are currently available | | | | | | |
| 8. | This examination does not exclude carrier status for other genetic conditions. | | | | | | |
| 9. | All data obtained from this analysis will be treated with strict confidentiality. | | | | | | |
| 10. | These DNA data (DNA sequences) are stored in a secure database. | | | | | | |
| 11. | My/my child's DNA sample, DNA sequences or clinical data can be exchanged with other genetic laboratories or used for research purposes, but that this always happens in pseudonymised form. | | | | | | |
| 12. | My/my child's DNA sample, DNA sequences or clinical data can be exchanged with other genetic laboratories as part of targeted research among my family members. | | | | | | |
| 13. | My/my child's data can be entered in a pseudonymised (coded) manner in an international database that can be consulted by registered researchers for non-commercial use and/or medical scientific research. | | | | | | |
| 14. | I can decide at any time to no longer participate in this study. No new data will then be generated from my/my child's DNA sample or DNA sequences. | | | | | | |
| 15. | For any further questions, I can always contact a physician at the Centre for Medical Genetics at Antwerp University Hospital. | | | | | | |
| l gi | ve my consent to genetic analysis by exome or genome sequencing: | | | | | | |
| in r | myself: YES 0 NO 0 in my child: YES 0 NO 0 | | | | | | |
| Naı | me: Date: | | | | | | |
| Sig | nature: | | | | | | |
| Naı | me of physician and date of signature: | | | | | | |
| Sig | nature of physican requesting consent: | | | | | | |