Print Form

# REQUEST FORM PRECONCEPTUAL GENETIC ANALYSIS

version1/20210901

Label sample female

Label sample male


**CENTRE FOR MEDICAL GENETICS**
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Universitair Ziekenhuis Brussel

BELAC 141-MED **BELAC 141-MED accrdietd according to quality standard ISO15189:2012**

## Identification female *

* Mandatory data

Name: Sticker
First name:
Date of birth:
Residential address: identification patient

Invoice address:

Email address:
Phone:
National registry N°:
Ethnic origin:

## Identification male *

Name: Sticker
First name:
Date of birth:
Residential address: identification patient

Invoice address:

Email address:
Phone:
National registry N°:
Ethnic origin:

## Carrier testing female*

| Sampling | Indication and genetic analysis | TAT |
|---|---|---|
| H E | ☐ Consanguinity | |
| | Fragiele-X syndrome/POI (FMR1 CGG-repeat) | 2-4 weeks |
| | Hemoglobinopathy *(after aberrant Hb-elektrophoresis)* | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| | ☐ Extended carrier testing *(€700/patient)* | 4-6 months |
| H E | ☐ IVF intake | |
| | Conventional karyotyping | 4-10 weeks |
| | Fragiele-X syndrome/POI (FMR1 CGG-repeat) | 2-4 weeks |
| | Spinale musculaire atrofie (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ Recurrent miscarriage >or=2 ☐ Recurrent implantation failure | |
| | Conventional karyotyping | 4-10 weeks |
| | Fragile-X syndrome/POI (FMR1 CGG-repeat) | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ Premature ovaran insufficiency (POI) | |
| | Conventional karyotyping | 4-10 weeks |
| | Fragiele-X syndrome/POI (FMR1 CGG-repeat) | 2-4 weeks |
| | Mucoviscidosis (CFTR frequent variants) | 2-4 weeks |
| | Premature ovarian insufficiency (POI gene panel) | 3-6 months |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ Candidate donor | |
| | Conventional karyotyping | 4-10 weeks |
| | Fragiele-X syndrome (FMR1 CGG-repeat) | 2-4 weeks |
| | Mucoviscidosis (CFTR frequent variants) | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ PGT-A intake ☐ PGT-SR intake ☐ PGT-M intake | |
| | Conventional karyotyping | 4-10 weeks |
| | Fragiele-X syndrome/POI (FMR1 CGG-repeat) | 2-4 weeks |
| | Hemoglobinopathy *after aberrant Hb-elektrophoresis)* | 2-4 weeks |
| | Mucoviscidosis (CFTR freq. variants) *(if partner carrier)* | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ Extended carrier testing *(non RIZIV/INAMI: €700/patient)* | |
| | Extended carrier testing (ECT gene panel) | 4-6 months |
| H E | ☐ Hypogonadotropic hypogonadism | |
| | Hypogonadotropic hypogonadism (HH gene panel) | 3-6 months |

## Carrier testing male *

| Sampling | Indication and genetic analysis | TAT |
|---|---|---|
| H E | ☐ Consanguinity | |
| | Mucoviscidosis (CFTR frequent variants) | 2-4 weeks |
| | Hemoglobinopathy *(na afwijkende Hb-elektrophoresis)* | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| | ☐ Extended carrier testing *(€700/patient)* | 4-6 months |
| H E | ☐ IVF intake | |
| | Conventional karyotyping | 4-10 weeks |
| | Mucoviscidosis (CFTR frequent variants) | 2-4 weeks |
| | Spinale musculaire atrofie (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ Recurrent miscarriage >or=2 ☐ Recurrent implantation failure | |
| | Conventional karyotyping | 4-10 weeks |
| | Mucoviscidosis (CFTR frequent variants) | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ Severe OAT ☐ CBAVD | |
| | Conventional karyotyping | 4-10 weeks |
| | Mucoviscidosis (CFTR frequent variants) | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| | Yq-microdeletions (AZFa,b,c) | 2-4 weeks |
| E | ☐ Macrozoospermia | |
| | AURKC | 2-3 months |
| H E | ☐ Candidate donor | |
| | Conventional karyotyping | 4-10 weeks |
| | Mucoviscidosis (CFTR frequent variants) | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ PGT-A intake ☐ PGT-SR intake ☐ PGT-M intake | |
| | Conventional karyotyping | 4-10 weeks |
| | Hemoglobinopathy *(after aberrant Hb-elektrophoresis)* | 2-4 weeks |
| | Mucoviscidosis (CFTR frequent variants) | 2-4 weeks |
| | Spinal muscular atrophy (SMN1 del ex7) | 2-4 weeks |
| H E | ☐ Extended carrier testing *(non RIZIV/INAMI: €700/patient)* | |
| | Extended carrier testing (ECT gene panel) | 4-6 months |
| H E | ☐ Hypogonadotropic hypogonadism | |
| | Hypogonadotropic hypogonadism (HH gene panel) | 3-6 months |

## Pre-implantation genetic testing female *

| Sampling | Indication and genetic analysis | TAT |
|---|---|---|
| E | ☐ PGT-M (monogenic) | 8-12 weeks |
| E | ☐ PGT-SR (chromosomal rearrangement) | 2-4 weeks |
| E | ☐ PGT-A (chromosomal aneuploidy) | 2-4 weeks |

## Pre-implantation genetic testing male *

| Sampling | Indication and genetic analysis | TAT |
|---|---|---|
| E | ☐ PGT-M (monogenic) | 8-12 weeks |
| E | ☐ PGT-SR (chromosomal rearrangement) | 2-4 weeks |
| E | ☐ PGT-A (chromosomal aneuploidy) | 2-4 weeks |

Legende H Na-Hep blood min. 7ml E EDTA blood min. 4ml.
We strive to complete the analyses within the set turnaround times (TAT). In exceptional situations, we may deviate from the standard TAT.

# INFORMED CONSENT FOR PRECONCEPTUAL GENETIC ANALYSIS

Universitair Ziekenhuis Brussel

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**To be completed by female *** *** Mandatory data** **To be completed by male ***

## GENETIC TEST

**1. Diagnostic genetic test**

I, the undersigned, agree to perform a diagnostic genetic test on a blood sample, or other samples, of the above person for the following condition:..... . The diagnostic genetic test that will be performed is:

☐ a limited analysis or 'targeted' analysis of gene(s) — a limited analysis or 'targeted' analysis of gene(s) ☐

☐ a broad analysis or 'non-targeted' genome-wide analysis** — a broad analysis or 'non-targeted' genome-wide analysis** ☐

**2. Scientific research**

After a diagnostic genetic test is done for a condition, some material usually remains. This material can be preserved as it can be useful for further diagnostic testing with broader genetic analyses** at a later date and/or for scientific research (see explanation below).
With regard to the preservation of remaining samples, the genetic data, and medical data for later scientific research:

☐ I agree — I agree ☐

☐ I do not agree — I do not agree ☐

**Broad genetic analysis:
Broad genetic analyses can lead to an incidental and/or secondary discovery of genetic results unrelated to the condition for which the test was performed. I realize that such results can have implications for myself and my family. I would like to be informed about genetic results that present an increased risk for diseases for which

☐ appropriate follow-up, prevention, or treatment is available (such as a risk for cancer, heart disease) ☐

☐ no prevention or treatments exist (such as for dementia; (NB only adult mentally competent persons may choose this option) ☐

**With regard to the storage and exchange of data/ samples as part of the diagnostic process and scientific research, I understand that:**

- the exchange of medical and genetic data between experts is important to improve knowledge of genetic diseases.
- this exchange can be done in the context of diagnostic testing and/or scientific projects approved by the relevant Ethics Committee.
- the exchange of data may lead to improved diagnosis for myself or others, improved healthcare, improved prevention, improved therapeutic means; and may be published in scientific journals, or presented at scientific meetings.
- my samples, genetic data, and relevant medical data are labelled with a code (see explanation on next page).
- my encoded genetic samples can be used as control material for the general improvement or development of tests.
- genetic and relevant medical data can be re-analyzed in the context of diagnostic tests that are available at a later stage and/or within approved research projects, without me being informed in advance.
- the knowledge and possibilities for analysis and interpretation of genetic research will increase in the future and re-analysis can reveal a (new) diagnosis. There is currently no systematic re-analysis of data.
- if my health insurance does not reimburse the costs for the original genetic test, these will be invoiced to me in full.
- I reserve the right to change my consent at any time, for one or more of the various points described. The withdrawal of consent will not adversely affect my general medical treatment (unrelated to the genetic test for which this consent was given). I understand that my withdrawal cannot be applied to the results and data collected before my request for withdrawal.
- my participation is voluntary and will not be linked to financial benefits.

☐ I agree with the above — I agree with the above ☐

☐ I do not agree with the above — I do not agree with the above ☐

**3. Informed consent**

I confirm that I am well informed about the objectives and nature of the analyses related to my condition. I received the necessary information from the healthcare provider and/or I read the corresponding information leaflet. I have had the time and opportunity to ask questions and I am satisfied with the answers and supplemented explanations.

Name female: Sticker
First name female:
Date of birth:
Residential address: identification patient
Email address:
Phone:
National registry N°:
Date:
Signature*:

Name male: Sticker
First name male:
Date of birth:
Residential address: identification patient
Email address:
Phone:
National registry N°:
Date:
Signature*:

**To be completed by healthcare provider ***

I hereby confirm that I have informed the undersigned patient and answered questions in the best possible way with regard to the possible results, limitations and options for the test(s) mentionned above.

Name:
First name:
Date:
Signature*: Stamp healthcare provider

Copy result to:
Address:

☐ Genetisch rapport in Nederlands ☐ Genetics report in English

**Identification referring physician ***

Name:
First name:
Referring service:
Address: Stamp referring physician
Email address:
Phone:
RIZIV/INAMI number:
Signature*:

Request date*:
Your reference:

# INFORMED CONSENT FOR PRECONCEPTUAL GENETIC ANALYSIS (continued)

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## EXPLANATION ON STORAGE AND USE OF SAMPLES

After a diagnostic genetic test is done, a part of the material remains for which there is no immediate purpose. This material could be destroyed, but often it is useful not to do so. In some cases, it can be used in a meaningful way. The following four possibilities are considered:

1) a different diagnostic test within the scope of your original question;

2) scientific research within the scope of your original question;

3) genetic research of a general nature, with which you mainly help other people;

4) you and/or your descendants have a new question or condition that requires genetic testing.

### Explanation

It is possible that a different diagnostic test is possible at a later date, for a condition that affects you or your family (1). Moreover, scientific research could be carried out in order to search for more understanding on this condition (2). The material that was previously obtained from you can be used for these tests. This material, and any encrypted medical data, will then be used further and examined at a national or international level. For research into rare diseases, such an approach can speed up the identification of an explanation for the condition. When performed, your data will always be encrypted in order to fully protect the privacy of you and your genetic and medical information.
Body material is often valuable for developing new scientific knowledge, or for testing diagnostic devices in the laboratory (3). This scientific knowledge is usually not directly applicable in practice at the beginning, but can become important for patients at a later date. A great deal of knowledge that is now used daily by doctors in patient care has arisen from such scientific research, of which the practical significance was initially not entirely clear.

### Examples of further use

1) and 2) After diagnostic genetic testing the remaining material is stored after use but identified via a code. This means that your personal data will be replaced by a random number. The list that indicates which number (code) belongs to which patient is stored by an administrator in a safe place. The people who use the material only see the random number (code) associated with the material. The code can be traced back to your personal data if a researcher - sometimes years later -finds a genetic change in a coded sample, which explains your original question or may be of interest to your state of health. An example is an inherited predisposition to cancer or to heart disease, for which prevention, treatment or surveillance options are available. The likelihood of finding such a genetic change is usually small. There is also a chance that we may find a genetic change that could affect your treatment, such as an adjustment in your medication. The researcher who makes such a discovery passes on the code number to the administrator who can link the code to the name of the patient and to the name of the practitioner/doctor with whom that patient has been in contact. Subsequently, an assessment is made on whether the genetic change is indeed important for you and your health. This assessment is done in consultation with an independent committee of doctors and other experts, which helps to decide whether the genetic change should be linked back to you. If so, you will be contacted by your treating physician to inform you of the genetic change. This finding will then have to be confirmed with a new independent test.
3) Your material can also be used for scientific research that only provides general knowledge and can not be individually applied. An example of this is when your material is used as a control sample for a test, which has nothing to do with the condition for which you had genetic testing in the first place. Samples and encrypted data from groups of patients are then compared with those of other groups of patients or healthy individuals. The results of such scientific research are usually not reported back to you. In the case that there would be feedback, it could be many years later.
4) After your original question has been answered, you and/or your descendants may have a new question concerning genetics. In that case, your sample can be used for a new genetic test.

### In conclusion

We hope to have given you sufficient information to make an informed decision about the storage and use of your samples and of your medical and genetic data. For more information, you may wish to contact the Medical Genetics Centre of UZ Brussel. https://www.uzbrussel.be/en/web/genetics
More information on privacy may be found at: https://www.uzbrussel.be/web/neem-zelf-uw-zorg-in-handen-/patiëntenrechten

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