

Label sample
fetusLabel sample
motherLabel sample
father

Universitair Ziekenhuis Brussel


<https://www.uzbrussel.be/web/centrum-voor-medische-genetica/>
 BELAC 141-MED accredited according to quality standard ISO15189
CENTRE FOR MEDICAL GENETICS
UZ BrusselLaarbeeklaan 101 - 1090 Brussel
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Identification mother *

* Mandatory data

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

Invoice address: _____

Email address: _____

Phone: _____

National registry N°: _____

Ethnic origin: _____

Identification fetus *

 Name: _____
 First name: _____
 Date of birth: _____
 National Registry N°: _____

Sample data fetus *

☐ CV Chorion villi
☐ AC Amniotic fluid
☐ NS Fetal blood (umbilical cord blood)
☐ FB Fetal biopsy Specify: _____
 ☐ DNA from Specify: _____
☐ Stock sample Reason: _____
 Collection date: _____

Sample mother *

☐ EDTA blood min. 4ml Collection date: _____ ☐ DNA

Sample father *

☐ EDTA blood min. 4ml Collection date: _____ ☐ DNA

Data pregnancy *

 Gestational age: _____ weeks _____ days
☐ Spontaneous ☐ IVF ☐ ICSI ☐ PGT ☐ egg donation ☐ sperm donation
 G: _____ P: _____ A: _____ ☐ Miscarriage ☐ TOP ☐ Extra uterine ☐ Mola

 Number of fetusses: ☐ 1 ☐ 2 ☐ vanishing twin
 Chorionicity: ☐ DC/DA ☐ MC/DA ☐ MC/MA

Indication *

☐ Fetal ultrasound anomaly(s) Specify: _____
☐ Aberrant NIPT Specify: _____
☐ Increased trisomy risk Specify: _____
☐ (Recurring) miscarriage Number: _____ Specify: _____
☐ History genetic disease

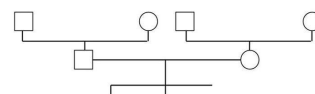
☐ In previous pregnancy/ies ☐ In mother ☐ In father ☐ In family ☐ Consanguinity Specify: _____

Clinical findings (preference HPO-terms):

addition clinical report required

Genetic defect in family member:

addition genetic report required

☐ Prereduction
☐ CMV / toxoplasmosis seroconversion
☐ HLA-compatibility
☐ Psycho-social
☐ Other Specify: _____

☐ man ☐ normal
☐ woman ☐ carrier
☐ fetus ☐ affected
 / deceased

Genetic test

Sampling fetus	Sampl. parent(s)	Prenatal test **	FB 1-12 weeks / ***: detailed information gene panel http://www.brightcore.be/gene-panels	TAT
CV AC FB NS	E	☐ Chromosomal analysis	☐ QF-PCR (chr X,Y,13,18,21) & CGH-array ☐ FISH: _____	**5-10 working days
CV AC FB	E	☐ Congenital malformation syndrome/MCA ☐ gene panel*** ☐ targeted: _____		2-6 months
CV AC FB NS	E	☐ Targeted mutation testing (monogenic) Specify: _____		10 working days

We strive to complete the analyses within the set turnaround times (TAT). In exceptional situations, we may deviate from the standard turnaround time



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D01-E

INFORMED CONSENT FOR GENETIC ANALYSIS AND RESEARCH

IDENTIFICATIE PATIËNT (* verplicht)

[Sticker ID patiënt]

I. PERMISSION FOR:

I consent to a diagnostic genetic test being performed on a blood sample, or other samples for the following condition:

.....

(tick one choice)

- ☐ LIMITED genetic analysis or TARGETED analysis of gene(s)
- ☐ WIDE genetic analysis or NON-TARGETED genome wide analysis

A wide genetic analysis could lead to incidental and/or secondary findings of genetic results unrelated to the condition for which the analysis was originally performed (such as risk for cancer, heart disease, or other conditions for which an appropriate prevention, follow-up or treatment is available).

I realise that such a diagnosis may have consequences for my family as well as for myself.

- ☐ I do not wish to be informed of such incidental and/or secondary genetic results.

II. RIGHT TO CHANGE PERMISSION

I have the right to withdraw my consent at any *time**. The withdrawal of my consent will be recorded in writing and added to my patient record. The healthcare provider will inform me of any possible consequences of withdrawing my consent on my further medical treatment.

**The change, however, does not apply to data and/or results already collected before my request to withdraw my consent.*

III. STORAGE AND EXCHANGE OF DATA/SAMPLES for DIAGNOSTICS and RESEARCH

I understand that:

- my medical data and genetic samples are coded (security method) so that they can be used for diagnostic, and/or scientific research approved by the Ethics Committee.
- the exchange of coded medical and genetic data between experts is important to improve (general) knowledge of genetic disorders and/or development of tests. This could lead to:
 - a better diagnosis for myself and/or others,
 - better healthcare and therapeutic options,
 - better prevention.

In addition, the results may be published in scientific journals or presented at scientific meetings.

- my data can be analysed again and more widely (re-analysis) in the context of improved diagnostics and approved research projects, without having to inform me in advance. Please note that no systematic re-analysis of data currently takes place.

IV. COSTS of diagnostic genetic analysis

If my health insurance does not cover the cost of genetic testing, I will be held liable.

V. VOLUNTARY participation

My participation is entirely voluntary and will in no way provide any financial benefits to me.

NOTES



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To be completed by the PATIENT or REPRESENTATIVE:

- I confirm that I have been properly informed regarding the objectives and nature of the analysis related to my condition.
- I received the necessary info from the healthcare provider and/or I received, read and understood the accompanying information leaflet.
- I have had time and opportunity to ask questions, and I am satisfied with the answers and additional explanations.

I give this consent informed, knowingly and freely.

Date:

Signature:

*If representative:

Relationship to patient:

Name and first name:

To be completed by the professional:

I hereby confirm that I have informed the signed patient/representative and answered questions in the best possible way regarding the possible results, limitations and options for the above genetic testing

Date:

Signature: [Stamp health care provider]

Notes on storage and use of medical (personal) data and bodily material

After genetic testing as part of your diagnostics, some material is often left over (residual material). This material can be stored for possible future use. The possible uses are explained below:

- **Diagnostic testing - new diagnostic test:** Your stored material can be reused later to investigate a genetic cause of a disorder of yourself or your family. Your data will be encrypted to protect your privacy. If an important discovery is made for you and your health, you *may* be informed through your treating physician. This finding will then have to be confirmed for you with an independent test.
- **Scientific research:** The material can also be used for scientific research, for example to develop new knowledge about genetic diseases. This may eventually become important for the treatment of other patients. Results are generally not reported back.
- **General genetic research:** The material may contribute to broader scientific research that helps others, for example in developing new treatments or testing new diagnostic devices in the laboratory. Your material can serve as control material in general research, without directly applying to you as an individual. This can help compare genetic data from patients and healthy individuals.
- **New genetic questions (from you or your relatives):** If new questions arise about the heredity of conditions, the material can be used again for genetic testing.

In conclusion

We hope this explanation will help you make an informed decision about the storage and use of your body material. For more information, please contact the Medical Genetics Centre at UZ Brussel at <https://www.uzbrussel.be/en/web/genetics>

For more information on privacy, please visit: <https://www.uzbrussel.be/web/international>