INFORMED CONSENT FORM

LABORATOIRE NATIONAL DE SANTE
NATIONAL CENTER OF GENETICS
Head: Prof. Dr Barbara Klink
Head of National Center of Genetics
1, rue Louis Rech
L-3555 Dudelange
Tel. (+352) 28 100 - 418
Fax. (+352) 28 100 -542
ncg-gen@lns.etat.lu

By signing below, I consent to the planned genetic analyses and the necessary tissue or blood sampling, for the purpose of investigating the following condition or suspected diagnosis:

.....

.....

I was informed

- that I have the right to withdraw my consent without giving any reasons, at any time.
- that I have the right not to be informed of test results.
- that I can stop the initiated analyses until the communication of the results at any time and that I can demand the destruction of all of my samples (incl. extracted components) and obtained data/results.

With your consent, unused sample material will be stored. Please decide if and how unused sample material may be used. I consent to the use of this material - for verifying the obtained results, laboratory quality assurance and future diagnostic investigations. - for the purposes of academic teaching and scientific research.	☐ **Yes** ☐ **No** ☐ **Yes** ☐ **No**
I consent being informed[1] of secondary/additional findings[2] if these have direct medical implications (e.g. possible prophylactic measures or therapeutic consequences) or may constitute a significant genetic risk for me or my family members. [1] According to current scientific understanding and based on the present recommendations of the American College of Medical Genetics and Genomics (ACMG). [2] Variants that may be obtained incidentally during the course of genetic testing and are associated with a condition other than the one for which testing was originally indicated.	☐ **Yes** ☐ **No**
If necessary, I consent that my sample material, my personal data and the test request is forwarded to a specialized cooperating laboratory or institute in order to investigate the above-stated condition in question.	☐ **Yes** ☐ **No**
I consent that data and test results collected in the context of the condition in question may be used in de-identified (pseudonymized) form for scientific research[1] and published in aNoymized form in medical journals. [1] e.g. to improve the understanding of the molecular pathogenesis and develop new diagnostic or treatment possibilities)	☐ **Yes** ☐ **No**
I consent that my personal data and test results will be stored longer than the statutory retention period of 10 years.[1] [1] In compliance with article 15(4) Loi du 24 juillet 2014 relative aux droits et obligations du patient, portant création d'un service national d'information et de médiation dans le domaine de la santé.	☐ **Yes** ☐ **No**
I consent that my test results may be used for the purpose of counseling and testing of at-risk family members.	☐ **Yes** ☐ **No**

Room for additional agreement(s):

……

I consent that the **results of the testing may be sent** to the following physicians or persons:

……

Name and signature of the responsible doctor

Place, Date .....

By signing this consent form, you confirm that the responsible medical personnel has informed you about the significance and consequences of the planned genetic testing. Further, the medical necessity and potential benefits of genetic testing were clearly communicated to you. In addition, possible health risks, which could arise from the collection of the sample material and the communication of the test result (e.g. psychological burden), were discussed in detail.

PATIENT DATA :	**LEGAL GUARDIAN :**	
Surename:	*Surename:*	*Surename:*
First name:	*First name:*	*First name:*
Matricule:	*Matricule:*	*Matricule:*
Place, date:	*Place, date:*	*Place, date:*
Signature:	*Signature::*	*Signature:*

CERTIFICATE OF CONSULTATION (ALTERNATIVE TO PATIENT CONSENT)

☐ I certify that I have informed the patient or his/her legal representative Mr/Ms ..... of the characteristics of the disease sought, the means of diagnosing it, the possibilities of prevention and treatment, the storage of his or her specimen, the possibility of subcontracting the analyses, and that I have obtained the consent of the patient or his or her guardianship under the conditions provided for in the above requirements.

Place ....., date ...../...../.....

Name and signature of the responsible doctor ……