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Optional complementary round

Preservation of dried blood samples collected as part of the
Québec Neonatal Blood Screening Program

Your participation in *Growing Up in Québec* does not oblige you to take part in this round, which is optional.



Growing Up
in Québec

Québec Longitudinal Study
of Child Development, 2nd edition

When your child was born, if you provided your consent, blood samples were collected from your child's heel to be screened for certain rare diseases as part of the Québec Neonatal Blood Screening Program (QNBSP). The Institut de la statistique du Québec (the Institut) would like to recover these samples. We require your consent to preserve and analyze these samples.

No new blood samples will be collected as part of this complementary round.

I authorize the Institut to:

1. **Provide** information that can identify my child to the Centre hospitalier universitaire de Québec, which keeps the dried blood samples collected when my child was born as part of the QNBSP;
2. **Preserve**, for 25 years, under the responsibility of the Institut, the dried blood samples collected under QNBSP for secondary research purposes and destroy them at the end of this time period;
3. **Make these samples available to researchers** for further laboratory analyses, solely for the purpose of conducting research relevant to the overall objective of the study. The researchers' projects will have to be submitted to and reviewed by the Institut's ethics committee. This secondary use of the samples is not part of QNBSP;
4. **Match** the biological data resulting from the analysis of these blood samples with other information collected in the study. This data matching will be done solely to carry out analyses relevant to the overall objective of the study;
5. **Send** the de-identified matched data (i.e., not revealing any name, address or telephone number) to partners and researchers who will have committed to respecting the Institut's standards regarding the security and confidentiality of information. The biological data will be treated as CONFIDENTIAL in accordance with the *Act respecting the Institut de la statistique du Québec* (CQLR, chapter I-13.011) and the *Act respecting Access to documents held by public bodies and the Protection of personal information*.

I agree

I refuse

CHILD

<input type="text"/>	<input type="text"/>
Child's first name (in capital letters)	Child's last name (in capital letters)
<input type="text"/>	<input type="text"/>
Name of birthplace (in capital letters) (e.g. name of hospital or birthing centre)	City of birthplace (in capital letters)

PARENT

<input type="text"/>	<input type="text"/>
Parent or legal representative's first name (in capital letters)	Parent or legal representative's last name (in capital letters)
Relationship to the child:	
<input type="checkbox"/> Biological or legal mother	<input type="checkbox"/> Biological or legal father
<input type="checkbox"/> Legal representative	
<input type="text"/>	<input type="text"/>
Signature	Date (YYYY / MM / DD)