Submitting DNA for the investigations of missing people



# A Family's Guide to the National Missing Persons DNA Program

Exhibit: National Inquiry into Missing and				
Murdered Indigenous Women and Girls				
Location/Phase: Part 2 Regina				
Witness: Brenda Butterworth-Carr				
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The National Missing Persons DNA
Program (the *Program*) was created to help investigations involving missing people or unidentified human remains. It is based on the voluntary submission of DNA profiles for comparison in the National DNA Data Bank. This guide will provide you with general information about the *Program* and the role that DNA might have in the investigation of a missing person.

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## THE VALUE OF DNA TO AN INVESTIGATION

'DNA' (deoxyribonucleic acid) is found in the genetic makeup of all living things. Each person's DNA is unique, which makes DNA testing one of the best methods to identify a person.

After other methods have been explored, the investigator will suggest the use of DNA as a way to provide potential leads in the investigations of missing people or when attempting to identify human remains. A DNA sample submitted under the National Missing Persons DNA Program (the *Program*) is analysed and the resulting DNA profile may then be compared to other DNA profiles that have been entered into the **National DNA Data Bank**. Canada's *DNA Identification Act* is specific about the types of comparisons in the National DNA Data Bank that are possible under the *Program*.

When family members volunteer to submit DNA to the *Program*:

- Their DNA profile is compared to the DNA profile obtained from the personal effects of the missing person. This comparison is done to establish whether the DNA profile developed from the personal effects comes from the missing person.
- A family member's DNA profile can also be compared in the National DNA Data Bank to the DNA profiles of unidentified human remains. This comparison is done to establish possible family associations and to potentially identify the human remains.

When submitting the personal effects of a missing person:

- The DNA profile obtained can be compared to the DNA profiles of unidentified human remains to determine if there is a match.
- The DNA profile can also be compared to unknown DNA profiles that have been collected from different police investigations. This type of comparison could serve to place a missing person at a crime scene and provide other potentially important information.

The results of the comparisons in the National DNA Data Bank may be immediate, long term or not happen at all.

## PARTICIPATION IN THE PROGRAM

# Voluntary consent

The submission of a family member's biological sample to the Program is completely voluntary. The investigator will provide families with a copy of a *consent form* that explains in detail the DNA comparisons that may be made with the DNA profile(s) being submitted. The consent form also provides information about the withdrawal of consent and other important details.

If a family member chooses to participate, consent must be provided in writing. Family members may choose not to provide consent and may do so without reprisal or fear of incrimination. If the consent form was signed and a family member has reconsidered, it is still possible to withdraw consent.

Take the time to become informed and understand what consent to the *Program* means. Obtain advice from different reliable sources before signing the consent form and before providing DNA for comparison in the National DNA Data Bank.

# Informed Understanding

A family member may choose to submit the personal effects of a missing person to the *Program* (e.g., toothbrush or used clothing). Participation is voluntary and based on having full knowledge and acceptance of the purposes for which the personal effects, the DNA profile, and information related to the DNA profile are to be used.

The investigator will request the family have an 'informed understanding' of what it means to submit the personal effects of a missing person under the *Program*. For example, it is important for the family to understand that a missing person's DNA profile is compared to numerous DNA profiles in the National DNA Data Bank including crime scene DNA. These comparisons may be used to help further the missing person investigation as well as any other police investigation. DNA matches to other police investigations could be used as evidence against the missing person in a criminal investigation and in a subsequent prosecution.

Family members may choose to not provide the biological sample of the missing person, without reprisal or fear of incrimination. However, without this biological sample, it may be more difficult to identify or locate the missing person.

## COLLECTING AND SUBMITTING DNA SAMPLES

If the family chooses to participate in the *Program*, investigators will collect samples that have biological (DNA) information. DNA can be collected from very small amounts of blood, a mouth (cheek) swab, or other samples. These samples are then submitted to be analysed and developed into a DNA profile.

# DNA from the personal effects of a missing person

The collection of a missing person's personal effects will involve identifying and locating items that have been used and handled exclusively by the missing person. The objective is to submit an item that has the best possibility of producing a DNA profile of the missing person.

Some personal effects are more useful in obtaining a DNA profile than others (see **Table 1**). A toothbrush or other personal items are often good sources of DNA. However, it is very important that these items were used only by the missing person or rarely used by anyone else. For example, a hairbrush used by the whole family would not be a good source of DNA for the missing person. In some cases, despite best efforts, it may not be possible to produce a DNA profile from the sample being submitted. The investigator may collect multiple items in the event that the missing person's DNA cannot be recovered from one or more of the items submitted.

Consider also if the missing person had surgery or blood work done and if a medical specimen may have been stored at the hospital or clinic. Ask the investigator for help in locating any known medical specimens and to assist in identifying the best samples to collect.

Table 1

DNA SOURCES	EXAMPLES	USEFULNESS
Medical Specimens	<ul> <li>bone marrow</li> <li>blood stored for elective surgery</li> <li>biopsy (tissue) sample</li> <li>pap smear</li> <li>newborn screen bloodspot</li> </ul>	most useful
Personal Items	<ul><li>toothbrush</li><li>hairbrush</li></ul>	very useful
Close Relatives	<ul> <li>DNA sample from biological parents of missing person</li> <li>DNA sample from biological children of missing person</li> <li>DNA sample from a blood brother/sister of missing person</li> </ul>	useful
Other Relatives	· DNA sample from the relatives of a missing person's biological mother (aunts, uncles, cousins, half-sisters or half-brothers)	less useful

#### DNA from relatives

DNA profiles from blood relatives can be used to confirm that the correct DNA profile has been obtained from the personal effects of the missing person. In the absence of the missing person's DNA profile (i.e. where it was not possible to develop a DNA profile from the personal effects or when no personal effect is available), the DNA profile from blood relatives may be used to make associations with the DNA profiles of unidentified human remains that are in the National DNA Data Bank.

The ability to associate a missing person to a family member depends on how closely related the family member is to the missing person. This is because DNA of close relatives is more similar than the DNA of distant relatives and because each person receives half their DNA from their mother and half from their father. The most useful DNA samples are from close blood relatives such as the missing person's biological mother, father, <u>children</u>, brothers or sisters.

In some cases, DNA from more distant relatives can be used. Specific relatives may be better suited than others to submit a DNA sample, depending on the DNA technology being used. DNA samples could be requested from a maternal relative of the missing person; for example, the missing person's aunt, uncle, or half-brothers or half-sisters on the mother's side of the family.

DNA from adoptive parents, adopted children, stepparents, or other non-blood relatives <u>cannot</u> be used to provide information about the genetic identity of a missing person but may be collected to exclude them as the donor of the profile on a personal effect.

The investigator will assess the requirements of each investigation and will consult with DNA experts of the *Program* to identify who the most suitable members of the family would be to submit their DNA.

#### DNA from children

When submitting the DNA sample of a missing person's biological child under the *Program*, it is also helpful to submit the DNA of that child's other biological parent.

Before collecting and submitting a DNA sample from a person under the age of 18, written consent from a parent or legal guardian is needed. Once the child reaches the age of eighteen, their direct written consent will be needed or their DNA profile will be removed from the National DNA Data Bank as of their 19<sup>th</sup> birthday.

## **DNA COMPARISONS**

The investigator will send collected samples of DNA to the National DNA Data Bank. Once a DNA profile is developed from the sample, the profile is entered into the National DNA Data Bank where comparisons begin immediately. The DNA profile remains in the National DNA Data Bank for comparison against future DNA profiles as they are added.

- **DNA profiles submitted by family members** are entered into the *Relatives of Missing Persons Index* (RMI) of the National DNA Data Bank and can only be compared against the DNA profiles from missing people or unidentified human remains. Family member DNA profiles cannot be compared against the DNA profiles from convicted offenders, crime scenes, or others in the National DNA Data Bank, and are not eligible for international comparison.
- DNA profiles developed from the personal effects of a missing person are entered into the
   Missing Persons Index (MPI) of the National DNA Data Bank and are compared against all other
   DNA profiles in the National DNA Data Bank. Visit the National DNA Data Bank website
   (www.rcmp-grc.gc.ca/nddb-bndg/index-accueil-eng.htm) to learn more.

DNA profiles from investigations across Canada are continuously being added to the National DNA Data Bank. A match or association could be made at any time. The results of DNA comparisons may be immediate, long term or not happen at all.

## Incidental findings

DNA comparisons may reveal information about family relationships that do not agree with the family's understanding. As a general rule, these types of incidental findings will not be revealed except where the disclosure of the finding is necessary to further the investigation.

## Commitment to Privacy

The DNA Identification Act establishes the authority for the National Missing Persons DNA Program and was written to respect Canadian privacy and safeguard personal information while providing for the humanitarian application of the National DNA Data Bank. Any comparisons made inside the National DNA Data Bank are strictly controlled.

DNA profiles are not retained when they are no longer necessary or when the consent has been withdrawn. Donors can withdraw consent at any time. Details are included in the Privacy Statement and consent forms that the investigator provides to the family before the samples are collected.

## NOTIFICATION OF A MATCH OR AN ASSOCIATION

The investigator will be informed when there is a match or an association to the DNA profile of a family member or to the personal effects of a missing person. While circumstances are different for each investigation and practices vary with each investigating agency, the investigator will contact the family directly with information that is relevant to the investigation.

### WITHDRAWING DNA FROM THE PROGRAM

DNA information can be withdrawn or removed from the *Program*:

- At the request of the family member who submitted a DNA sample. DNA submitted to the *Program* can be withdrawn at any time. To withdraw consent, the family member must notify the local police or investigating agency, in writing. The police will contact the *Program* to remove and destroy the biological sample and to remove your DNA profile and related information from the National DNA Data Bank. After the DNA profiles and related information are removed from the NDDB, no further comparisons can be made.
- When the investigation is resolved. When a missing person investigation is resolved, DNA profiles submitted for that investigation will be destroyed.
- When the legislation requires its removal by the *Program*. The removal and destruction of DNA information provided by a family member will automatically occur after five years if the investigator has not updated the *Program* regarding the conditions required to retain the information.

# CONTACT

- The investigating agency for the missing person's case is your **first point of contact** for all inquiries, questions and requests about the *Program*.
- Concerns related to the collection, use, disclosure or retention of personal information under the *Program* should be referred to the Office of the Privacy Commissioner of Canada:
  - Office of the Privacy Commissioner of Canada
     30 Victoria Street
     Gatineau, Quebec K1A 1H3
  - **1**-800-282-1376 (toll-free)
  - https://www.priv.gc.ca/en/report-a-concern/file-a-formal-privacy-complaint/