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The Parliament of the  
Commonwealth of Australia

THE SENATE

*Presented and read a first time*

## **Genetic Privacy and Non-discrimination Bill 1998**

**No.     , 1998**

*(Senator Stott Despoja)*

**A Bill for an Act to protect the genetic privacy of  
individuals, to prohibit genetic discrimination and  
to provide for the collection, storage and analysis of  
DNA samples, and for related purposes**



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1 **A Bill for an Act to protect the genetic privacy of**  
2 **individuals, to prohibit genetic discrimination and**  
3 **to provide for the collection, storage and analysis of**  
4 **DNA samples, and for related purposes**

5 The Parliament of Australia enacts:

6 **Part 1—Preliminary**  
7

Section 1

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1 **1 Short title**

2 This Act may be cited as the *Genetic Privacy and Non-*  
3 *discrimination Act 1998.*

4 **2 Commencement**

5 This Act commences on a day to be fixed by Proclamation.

6 **3 Saving of certain State and Territory laws**

7 It is the intention of the Parliament that this Act is not to affect the  
8 operation of a law of a State or of a Territory that is capable of  
9 operating concurrently with this Act.

10 **4 Act to bind the Crown**

11 (1) This Act binds the Crown in right of the Commonwealth, of each  
12 of the States, of the Australian Capital Territory, of the Northern  
13 Territory and of Norfolk Island.

14 (2) This Act does not make the Crown liable to be prosecuted for an  
15 offence.

16 **5 Extension to external Territories**

17 This Act extends to every external Territory.

18 **6 Objects of Act**

19 The objects of this Act are:

20 (a) to define the circumstances under which:

21 (i) genetic information may be collected, stored, analysed  
22 and disclosed; and

23 (ii) DNA samples may be collected, stored and analysed;  
24 and

- 1 (b) to define the rights of individuals and persons with respect to  
2 genetic information; and  
3 (c) to define the responsibilities of persons with respect to  
4 genetic information; and  
5 (d) to protect individuals and families from genetic  
6 discrimination; and  
7 (e) to establish uniform rules that protect individual genetic  
8 privacy; and  
9 (f) to establish effective mechanisms to enforce the rights and  
10 responsibilities established under this Act.

## 11 **7 Interpretation**

12 In this Act, unless the contrary intention appears:

13 *collect* means to obtain a DNA sample.

14 *Convention* means any international agreement to which Australia  
15 is a party or has signified agreement.

16 *disclose*, when used with respect to the genetic information of an  
17 individual, means to convey, or provide access to, the genetic  
18 information to a person other than the individual.

19 *DNA* means deoxyribonucleic acid, which is a genetic material that  
20 is composed of nucleotides, that encode genetic information.

21 *DNA sample* includes:

- 22 (a) a human tissue sample from which DNA is intended to be  
23 extracted; or  
24 (b) DNA extracted from such tissue sample and other molecules  
25 (such as ribonucleic acids and polypeptides) from which  
26 DNA may be derived;

27 but does not include a tissue sample that is taken:

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1 (c) as a biopsy or an autopsy specimen, or as a clinical specimen  
2 solely for the purpose of conducting an immediate clinical or  
3 diagnostic test that is not a DNA test; or

4 (d) as a blood sample solely for the purpose of storage in and  
5 distribution by a blood bank.

6 **family** means the biological and legal relatives of an individual  
7 who may have a material interest in the genetic information of the  
8 individual.

9 **genetic analysis** means the process of characterising genetic  
10 information from a DNA sample.

11 **genetic information** means:

- 12 (a) information from a DNA sample about genotype; or  
13 (b) information from mutation analysis; or  
14 (c) information about nucleotide and polypeptide sequence(s); or  
15 (d) information about gene(s) or gene products.

16 **genetic record** means information (including information forming  
17 part of a database), whether compiled lawfully or unlawfully, and  
18 whether recorded in a material form or not, that records genetic  
19 information of an individual in a manner connecting it with the  
20 person's identity.

21 **genetic services** means any service providing genetic analysis.

22 **individual** means the source of a human tissue sample from which  
23 DNA is extracted or genetic information is characterised. The term  
24 includes a subject of genetic research and, where appropriate,  
25 includes the parent, guardian or legal representative of the  
26 individual.

27 **individual identifier** means any information by which the identity  
28 of the individual can be ascertained, but does not include codes that  
29 cannot be used singly to identify an individual.

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1                    **insurer** means an insurer within the meaning of paragraph 51(xiv)  
2                    of the Constitution.

3                    **person** includes a family, corporation, partnership, association,  
4                    joint venture, a body (whether incorporated or not) established for  
5                    a public purpose by or under a law of the Commonwealth, and any  
6                    other legal or commercial entity. The term **person**, used with  
7                    respect to a human tissue sample, does not include the individual  
8                    who is the source of the tissue sample.

9                    **research** means scientific investigation that includes systematic  
10                    development and testing of hypotheses for the purpose of  
11                    increasing knowledge.

12                    **researcher** means a person who conducts research.

13                    **retain** means to store a DNA sample or genetic information  
14                    characterised from such a sample for an extended period of time  
15                    after the initial genetic analysis.

16                    **subject**, when used with respect to genetic research, means the  
17                    source of a human tissue sample collected for genetic analysis.

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**Part 2—Disclosure of genetic information to third persons**

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**8 Disclosure of genetic information**

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(1) A person may disclose genetic information in a genetic record characterised from the DNA sample of an individual only if:

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(a) the individual has authorised the disclosure; or

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(b) the disclosure is required or authorised by or under law; or

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(c) the person believes on reasonable grounds that the disclosure is necessary to prevent or lessen a serious and imminent threat to the life or health of the individual or of another person.

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(2) The person to whom genetic information has been disclosed may redisclose the information only to the extent reasonable in the exercise of judgment for professional medical consultation for the direct benefit of a patient or with the written authorisation of the individual.

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**9 Authorisation for disclosure**

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(1) To be valid, the authorisation by an individual must comply with each of the following:

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(a) the authorisation must be in writing, signed by the individual, and dated on the day of signature; and

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(b) the authorisation must identify the person authorised to make the disclosure; and

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(c) the authorisation must describe the specific genetic information to be disclosed; and

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(d) the authorisation must identify the person to whom the genetic information is to be disclosed; and

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- 1 (e) the authorisation must describe the purpose for which the  
2 disclosure is being made; and
- 3 (f) the authorisation must state the date upon which the  
4 authorisation will expire; and
- 5 (g) the authorisation must include a statement that the  
6 authorisation for disclosure of genetic information may be  
7 revoked or amended at any time prior to the disclosure.
- 8 (2) A copy of the authorisation is to be provided to the individual and a  
9 copy of the authorisation retained with the genetic record.
- 10 (3) An individual may revoke or amend the authorisation at any time  
11 before the disclosure. The revocation or amendment must be in  
12 writing and addressed to the person who stores the genetic  
13 information.
- 14 (4) Each disclosure made pursuant to the authorisation must be  
15 accompanied by the statements set out in Schedule 1.
- 16 (5) A general authorisation for the release of records or medical  
17 information is not to be construed as an authorisation for disclosure  
18 of genetic information. With respect to records that contain genetic  
19 information, the requirements for disclosure of genetic information  
20 that are described in this section are to be fulfilled prior to  
21 disclosure of the information.

## 22 **10 Inspection and copying of genetic records**

- 23 (1) A person who retains the genetic information of an individual in  
24 genetic records must, on written request, permit the individual to  
25 inspect the genetic records containing the genetic information and  
26 may provide a copy of any such records to the individual.
- 27 (2) A person described in subsection (1) who receives a written request  
28 from an individual to inspect or copy genetic records must, not  
29 later than 30 days after receiving the request, make the information  
30 available to the individual. The person may make the information  
31 available by permitting the individual to inspect the genetic records
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- 1                   during business hours, or by delivering a copy of the genetic  
2                   records to the individual.
- 3                   (3) A person must provide a non-technical explanation of terms, and  
4                   any codes or abbreviations, used in the genetic records of the  
5                   individual requesting the genetic records.
- 6                   (4) The person may charge an individual (except an individual who  
7                   participates as a subject in a research project) a reasonable fee, for  
8                   copies of genetic records that are provided under section 16. The  
9                   fee must not exceed the actual duplication costs, including  
10                  administrative costs, to the person providing the copies.

11                  **11 Amendment of genetic records**

- 12                  (1) Not later than 30 days after receiving a written request by an  
13                  individual to amend any genetic records, a person who retains the  
14                  genetic information in the records must either agree or refuse to  
15                  add the written amendment to the record. The person must make  
16                  the amendment if such information is not accurate or complete for  
17                  the purposes for which such information may be used or disclosed  
18                  by the person.
- 19                  (2) If the person retaining the information agrees to make an  
20                  amendment under subsection (1), the person must, not later than 30  
21                  days after such receipt:  
22                          (a) make the amendment requested; and  
23                          (b) inform the individual that the amendment has been made; and  
24                          (c) make reasonable efforts to inform any other person to whom  
25                          the information was previously disclosed of the amendment.
- 26                  (3) If the person retaining the information refuses to make an  
27                  amendment under subsection (1), not later than 30 days after such  
28                  receipt, the person must inform the individual in writing of:  
29                          (a) the reasons for the refusal of the person to make the  
30                          amendment; and  
31                          (b) the procedures for further review of the refusal; and
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- 1 (c) the right of the individual to provide the person with a  
2 concise written statement setting out the requested  
3 amendment and the reasons of the individual for disagreeing  
4 with the refusal of the person to make the amendment.
- 5 (4) After an individual has provided a statement of disagreement under  
6 paragraph (3)(c), the person storing the records:
- 7 (a) must make the statement part of the records of the individual;  
8 and
- 9 (b) in any subsequent disclosure of the disputed portion of the  
10 genetic information, shall include a copy of the statement and  
11 may include a statement of the reasons for not making the  
12 requested amendment.

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2 **Part 3—Collection, storage and analysis of DNA**  
3 **samples**

4 **12 Collection of samples**

- 5 (1) Except as otherwise provided by law, a person may collect a DNA  
6 sample from an individual for genetic analysis, only if the person:  
7 (a) obtains the written authorisation of the individual in  
8 accordance with section 16; and  
9 (b) provides the information to the individual in accordance with  
10 section 15; and  
11 (c) provides the notice of rights and assurances in accordance  
12 with section 14; and  
13 (d) collects the sample in accordance with the authorisation and  
14 notice of rights and assurances.

15 **13 Storage of DNA sample and conduct of genetic analysis**

16 Except as otherwise required by law, a person may store or conduct  
17 a genetic analysis of a DNA sample from an individual, only if the  
18 person:

- 19 (a) has the written authorisation of the individual and the notice  
20 of rights and assurances has been provided; and  
21 (b) stores or conducts the analysis of the DNA sample in  
22 accordance with the authorisation and notice of rights and  
23 assurances.

24 **14 Notice of rights and assurances**

25 The person who collects the DNA sample for genetic analysis must  
26 provide the individual, prior to the collection of the DNA sample,  
27 and any other person upon request, with a written notice of rights  
28 and assurances that contains the following information and  
29 assurances:

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- 1 (a) that the DNA sample will be used only as authorised in the  
2 written authorisation; and
- 3 (b) that the individual has the right to order the destruction of an  
4 identifiable DNA sample at any time; and
- 5 (c) that the DNA sample will be destroyed upon the completion  
6 of the genetic analysis or the genetic test, unless the  
7 individual has consented in writing to further use of the  
8 sample; and
- 9 (d) that the individual may specify another person as the person  
10 authorised to make decisions regarding disposition of the  
11 DNA sample after the death of the individual and, if any  
12 person is so designated, that the individual should notify the  
13 facility in which the DNA sample is stored; and
- 14 (e) that the individual has the right to examine records  
15 containing genetic information, to obtain copies of such  
16 records, and to request amendment of such records; and
- 17 (f) that researchers may be granted access to a DNA sample only  
18 as specified in the written authorisation of the individual; and
- 19 (g) that the collection, storage and analysis of the DNA sample  
20 and the genetic information characterised from the sample are  
21 protected by this Act, and that an individual whose rights  
22 under this Act are violated may seek redress as provided for  
23 in this Act; and
- 24 (h) about the availability, or the lack of availability, of optional  
25 genetic counselling.

26 **15 Information to be provided to the individual**

27 Prior to the collection of a DNA sample from an individual for  
28 genetic analysis, the person who collects the sample must inform  
29 the individual, in language understandable to the individual:

- 30 (a) that consent to the collection of the DNA sample is  
31 voluntary; and
- 32 (b) about the genetic information that can reasonably be expected  
33 to be derived from the genetic analysis; and
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- 1 (c) about the implications of genetic information derived from
- 2 the genetic analysis, for the individual and the family
- 3 members of the individual; and
- 4 (d) about the ways in which the genetic information derived from
- 5 the genetic analysis will be used; and
- 6 (e) about the information that the individual can expect to
- 7 receive on completion of the genetic analysis; and
- 8 (f) about the extent of the right of the individual to have the
- 9 DNA sample removed from a research study and, if possible,
- 10 to have the genetic information characterised from the DNA
- 11 sample destroyed; and
- 12 (g) about the right of the individual to revoke consent to the
- 13 genetic analysis at any time prior to the commencement of
- 14 the genetic analysis; and
- 15 (h) that revocation of consent for genetic analysis does not
- 16 absolve the individual of responsibility for all relevant costs
- 17 of the genetic analysis; and
- 18 (i) that the genetic analysis may yield information that should be
- 19 communicated to a family member of the individual; and
- 20 (j) about the existence of, and protections afforded by, this Act;
- 21 and
- 22 (k) about the availability, or the lack of availability, of optional
- 23 genetic counselling.

24 **16 Authorisation to collect, store and analyse DNA samples**

- 25 (1) To be valid, the authorisation by an individual must comply with
- 26 each of the following:
- 27 (a) the authorisation must be in writing, signed by the individual,
- 28 and dated on the day of signature; and
- 29 (b) the authorisation must identify the person authorised to
- 30 collect the DNA sample; and
- 31 (c) the authorisation must state the tissue to be collected and the
- 32 method of collection; and

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- 1 (d) the authorisation must include a description of all authorised  
2 uses of the DNA sample; and
- 3 (e) the authorisation must indicate whether the individual  
4 permits the sample to be retained after the analysis is  
5 completed, and if not, how the sample is to be disposed of  
6 after the analysis; and
- 7 (f) the authorisation must include provisions that permit the  
8 individual to consent to:
- 9 (i) use of the DNA sample for research; and
- 10 (ii) commercial use of the DNA sample, with a waiver of, or  
11 a provision for, economic benefit to the individual; and
- 12 (iii) if the individual consents to use under subparagraph (i)  
13 or (ii), use without identifiers, or use with individual  
14 identifiers or codes retained, of the DNA sample; and
- 15 (iv) notification, if individual identifiers or codes are  
16 retained, about information resulting from such use that  
17 may have implications for the individual or a family  
18 member of the individual; and
- 19 (g) the authorisation must comply with additional provisions  
20 requiring informed consent by human subjects in research.
- 21 (2) The authorisation must be retained for the period during which the  
22 DNA sample is collected, analysed and stored.
- 23 (3) A copy of the completed authorisation must be provided to the  
24 individual.

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2 **Part 4—Discrimination prohibited**

3 **17 Genetic discrimination to be unlawful.**

- 4 (1) It is unlawful for a person to do any act involving a distinction,  
5 exclusion, restriction or preference based on genetic information  
6 which has the purpose or effect of nullifying or impairing the  
7 recognition, enjoyment or exercise, on an equal footing, of any  
8 human right or fundamental freedom in the political, economic,  
9 social, cultural or any other field of public life.
- 10 (2) The reference in subsection (1) to a human right or fundamental  
11 freedom in the political, economic, social, cultural or any other  
12 field of public life includes a reference to any right of a kind  
13 referred to in a Convention.
- 14 (3) Subsection (1) does not apply in respect of the employment and  
15 insurance of persons, except as provided in this Part.
- 16 (4) The succeeding provisions of this Part do not limit the generality of  
17 subsection (1).

18 **18 Discrimination by employers or potential employers**

19 An employer may request or require or use the genetic information  
20 of an employee for the purpose of:

- 21 (a) permitting a genetically susceptible employee to avoid  
22 occupational exposure to substances with a mutagenic or  
23 teratogenic effect; or  
24 (b) determining a genotype that is otherwise directly related to  
25 the work and is consistent with business necessity;

26 but an employer must not request, require, or use the genetic  
27 information of an employee or a prospective employee for any  
28 purpose restricting any right or benefit otherwise due or available  
29 to the employee or the prospective employee.

**19 Discrimination by insurers**

An insurer may request or require or use the genetic information of an individual if the genetic information from a genetic analysis has already been undertaken and a genetic record exists, but an insurer must not:

- (a) terminate, restrict, limit, refuse to renew, or otherwise apply conditions to the coverage of an individual or family member under the policy or plan involved, or restrict the sale of the policy or plan to an individual or family member on the basis of any genetic information about a healthy individual or a healthy family member, or on the basis of a request for or receipt of genetic services by an individual or family member; or
- (b) discriminate against an individual's family in the provision of insurance coverage; or
- (c) require an applicant for insurance coverage, or an individual or family member who is enrolled under an insurance coverage policy or plan, to be subjected to genetic analysis or to be questioned about genetic information.

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2 **Part 5—Research**

3 **20 Research involving genetic analysis**

- 4 (1) A DNA sample may be analysed as part of a research project only  
5 if the researcher has determined that:
- 6 (a) use of DNA samples is essential to the research project; and
  - 7 (b) the potential benefit of the research project to society  
8 outweighs the potential risks to the research subjects,  
9 including psychosocial risks and intrusion into the privacy of  
10 the subjects that would result from genetic analysis of DNA  
11 samples; and
  - 12 (c) the research protocol:
    - 13 (i) contains adequate safeguards to protect against  
14 disclosure of genetic information that is generated by  
15 the research; and
    - 16 (ii) satisfies the requirements of section 12; and
    - 17 (iii) describes the intended uses of the DNA samples; and
    - 18 (iv) prohibits inclusion of specific molecular genetic  
19 genotype information in records unless the subjects  
20 authorise such inclusion in writing; and
    - 21 (v) with respect to protocols involving the use of DNA  
22 samples from subjects deceased prior to the  
23 commencement of this Act:
      - 24 (A) provides a reasonable method for disclosing to  
25 the family members of a subject, the risks that  
26 are associated with genetic information of the  
27 subject that is generated by the research, and in  
28 reasonable medical judgment, can be effectively  
29 ameliorated, prevented or treated; and
      - 30 (B) takes into account the right of family members  
31 to refuse to be informed about the genetic  
32 information; and
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- 1 (vi) describes the availability, or lack of availability, of  
2 genetic counselling related to the research project.
- 3 (2) For purposes of subparagraph (1)(c)(i), adequate safeguards against  
4 disclosure of genetic information, at a minimum, include:
- 5 (a) satisfying any guidelines issued by the National Health and  
6 Medical Research Council and approved by the Privacy  
7 Commissioner under section 95 of the *Privacy Act 1988*; and  
8 (b) ensuring that research subjects will not be identifiable in any  
9 report or publication that results from the research without  
10 their authorisation; and  
11 (c) having procedures to remove or destroy any individual  
12 identifiers at the earliest opportunity, consistent with the  
13 purposes of the project and the terms of the authorisation of  
14 the subjects involved.
- 15 (3) If the DNA sample of a subject is collected, stored or analysed in  
16 connection with a research project, the researcher must ensure the  
17 destruction of the DNA sample on the date of completion of the  
18 project or withdrawal of the subject from the project, whichever  
19 occurs first, unless the researcher obtains a specific authorisation of  
20 the subject according to the provisions of this Act, to store the  
21 sample after such date.
- 22 (4) If a research project includes genetic analysis of the family  
23 members of a subject for pedigree analysis or linkage analysis:
- 24 (a) the genotype records must be stored in strict confidentiality;  
25 and  
26 (b) the process for obtaining the authorisation of the subject must  
27 include information about:
- 28 (i) the possibility that family members of the subject may  
29 learn genetic information about the subject as a result of  
30 a project; and  
31 (ii) the possibility that the project may determine that some  
32 family members are not genetic relatives; and
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- 1 (iii) the disposition of records and data generated during the  
2 project; and  
3 (c) the genetic information must only be disclosed according to  
4 the requirements of this Act.

5 **21 Disclosure of genetic information for research purposes**

- 6 (1) Any person who stores genetic information of a subject may allow  
7 access to such information only with the written authorisation of  
8 the subject according to the provisions of this Act, and such  
9 information must be provided with individual identifiers, or codes,  
10 or no identifiers, according to the written authorisation of the  
11 subject.
- 12 (2) Notwithstanding subsection (1), a person who stores genetic  
13 information may grant access to such information solely for the  
14 purpose of inspection or review of the records containing the  
15 information if:
- 16 (a) the inspection or review is for the purpose of compiling data  
17 for statistical or epidemiological studies and genetic  
18 information that contains personal identifiers is not copied,  
19 removed from the records, or redisclosed in any way; and  
20 (b) the person conducting the inspection or review certifies in  
21 writing:
- 22 (i) that the limitations in paragraph (a) will be complied  
23 with; and  
24 (ii) that the person has complied with this Act; and  
25 (iii) that the person has knowledge of liability for breaches  
26 of this Act.

27 **22 DNA samples collected prior to the commencement date**

- 28 (1) A DNA sample collected before the commencement of this Act  
29 may be analysed as part of a research project, unless the individual  
30 involved, within 3 years of the commencement of this Act, submits  
31 a written request that such sample be withdrawn or destroyed.
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- 1                   (2) Except as provided by this Act, genetic information collected as  
2                   part of a research project described in this section may be disclosed  
3                   only with the authorisation of the individual involved or the  
4                   individual's legal representative.

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2 **Part 6—Miscellaneous**

3 **23 Transferred possession of DNA samples**

- 4 (1) Any person in possession of DNA samples and genetic  
5 information, who intends to transfer control of, or discontinue,  
6 activities or services related to the analysis of DNA samples, must  
7 inform the individual that the individual has the right to:  
8 (a) consent to the transfer of the samples or records containing  
9 the genetic information; or  
10 (b) order that the samples or records be returned to the  
11 individual; or  
12 (c) order that the samples or records be destroyed.
- 13 (2) If, within a period of 3 months after notification pursuant to  
14 subsection (1), the person receives no response from the individual,  
15 the person:  
16 (a) may destroy the samples or the records if the activities or  
17 services are discontinued; or  
18 (b) may place the samples and research records, without  
19 individual identifiers, in a tissue sample archive, according to  
20 prior instructions of the individual; or  
21 (c) may proceed with the intended transfer of the samples and  
22 records.

23 **24 Genetic information, etc. derived from the unborn**

- 24 (1) Where genetic information is available from genetic analysis  
25 before the birth of a person and about that person's genome, the  
26 genetic information is the genetic information of the person's  
27 biological mother but becomes the genetic information of that  
28 person when he or she is born alive.

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- 1                   (2) This section applies only to genetic information derived from the  
2                   genome of the person, and does not include genetic information  
3                   about other genomes.
- 4                   (3) For the purposes of this Act, a person to whom subsection (1)  
5                   applies is an individual.

Section 25

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**Part 7—Privacy and discrimination complaints**

**25 Investigation and determinations by the Privacy Commissioner**

- (1) An individual may complain about an act or practice that may be an interference with the privacy of the individual according to this Act by making a complaint to the Privacy Commissioner.
- (2) Where a complaint has been made to the Privacy Commissioner under this section, Part V of the *Privacy Act 1988* (except for paragraph 41(3)(a) and subsections 41(4), 52(3A) and 63(1)) applies as if the complaint were a complaint under section 36 of that Act.

**26 Investigation and determinations by HREOC**

- (1) An individual may complain about an act or practice that may be genetic discrimination according to this Act by making a complaint to the Human Rights and Equal Opportunity Commission.
- (2) Where a complaint has been made to the Human Rights and Equal Opportunity Commissioner under this section, Division 3 of Part II of the *Human Rights and Equal Opportunity Commission Act 1986* (except for section 29) applies as if the complaint were a complaint under section 20 of that Act.

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**Part 8—Other breaches and penalties****27 Action for damages etc.**

- (1) This Part applies only if Part 7 does not apply.
- (2) Any individual whose rights under this Act have been breached may maintain an action for damages or equitable relief, as provided for in this Part.
- (3) In any action brought under this section, a court may order:
  - (a) a person to comply with the provisions of this Act; and
  - (b) any other appropriate equitable relief.
- (4) Any person who negligently collects, stores or analyses a DNA sample of an individual in breach of this Act, or negligently induces another person to conduct such collection, storage or analysis, is liable to the individual for each such breach in an amount equal to:
  - (a) any actual damages sustained as a result of the collection, storage or analysis, or \$50 000, or an amount determined by the court, whichever is greatest; and
  - (b) in any case in which such breach has resulted in profit or monetary gain, treble damages; and
  - (c) in the case of a successful action under this section, the costs of the action and reasonable costs as determined by the court.
- (5) Any person who wilfully collects, stores or analyses a DNA sample of an individual in breach of this Act, or wilfully induces another person to conduct such collection, storage or analysis, shall be liable to the individual for each such breach in an amount equal to:
  - (a) any actual damages sustained as a result of the collection, storage or analysis, or \$100,000, or an amount determined by the court, whichever is greatest; and

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- 1                           (b) such punitive damages as the court may allow; and  
2                           (c) in the case of a successful action under this section, the costs of the  
3                           action as determined by the court.

1 **Schedule 1—Notice to accompany disclosures**  
2

3 The following written statement must accompany each disclosure:

4 This information is obtained from the DNA sample of an  
5 individual and has been disclosed to you from confidential records  
6 protected under the *Genetic Privacy and Non-discrimination Act*  
7 *1998*. Any further disclosure of the information without specific  
8 written authorisation of the individual is prohibited and is subject  
9 to the penalties under the *Genetic Privacy and Non-discrimination*  
10 *Act 1998*.



