An Roinn Leanaí, Comhionannais,
Míchumais, Lánpháirtíochta agus Óige
Department of Children, Equality,
Disability, Integration and Youth

Birth Information and Tracing Act 2022

Policy Guidelines

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Birth Information and Tracing Act 2022 - Policy Guidelines

Contents

1. Introduction and Glossary

1.1. Introduction

The Birth Information and Tracing Act 2022 enshrines in law the importance of a person knowing their origins. In accordance with this fundamental objective, it provides for the following four services:

a) **Information Service:** the legislation provides for the full release of birth certificates, as well as the full release of birth, early life, care and medical information as defined in the legislation, to all relevant persons who have attained the age of 16 years. It also provides for the release of information, in specified circumstances, to their son, daughter or next of kin.
b) **Tracing Service:** the legislation establishes a statutory tracing service to support and assist people actively seeking to share information or make contact with family.
c) **Contact Preference Register:** the legislation also establishes a statutory contact preference register where people can register their wishes in relation to contact with family, as well as provide contact details, information and items for sharing with specified family members. In contrast to the tracing service which supports people who are actively seeking contact, the register is a way for people to signal all contact preferences, from a willingness to be contacted to a wish for privacy. It also provides a mechanism to lodge information to be provided only in the event that the intended recipient chooses to come forward.
d) **Safeguarding of Records:** the legislation provides for the safeguarding of adoption and other relevant records and provides important mechanisms for records to be identified and taken into State ownership by the Adoption Authority of Ireland. As such, it represents an important starting point in fulfilling Government commitments to a central repository of records housed within a National Centre for Research and Remembrance.

Information on how to apply for an Information Service, Tracing Service or an entry in the Contact Preference Register is available at birthinfo.ie or can be accessed by calling AAI at 01 2309 300 or Tusla at 0818 44 55 00. Support is also available from the Adoption Authority of Ireland and from Tusla to any person who needs assistance in making an application for one of these services.

In addition to the four services listed above, the legislation contains important, bespoke measures to address the issues arising for people affected by **illegal birth registration**. Some of these relate to the provision of information, access to tracing services or assurance on contracts and are, therefore, covered by relevant chapters of these guidelines. Other bespoke measures are set out in Parts 8 and 9 of the Birth Information and Tracing Act. As these Parts fall under the remit of the Minister for Justice and the Minister for Social Protection respectively, they are not covered by the present guidelines made by the Minister for Children, Equality, Disability, Integration and Youth. However, information on the measures provided under Parts 8 and 9 of the legislation will be published alongside these guidelines.

1.2. Status and Purpose of Guidelines

These policy guidelines are made under sections 16, 19, 24, 25, 31, and 37 of the Birth Information and Tracing Act 2022 by the Minister for Children, Equality, Disability, Integration and Youth.

The Birth Information and Tracing Act 2022 provides the legislative basis for the suite of services set out at (a) to (d) above. The purpose of the guidelines is to provide detailed Ministerial guidance on the operation of the services, reflecting the primary legislation and any secondary legislation in

force. It is also intended that these guidelines will provide a 'plain English' and user-friendly explanation of the legislation, although they do not purport to be a legal interpretation.

At an operational level, it is envisaged that the guidelines will aid the development and implementation of consistent and user-friendly operating procedures by each body delivering services under the Act.

1.3. Glossary

When terms appearing in this glossary are used in the guidelines below, they will appear in *italics.*

Agency means the Child and Family Agency, Tusla.

Authority means the Adoption Authority of Ireland.

Designated person is a person engaged by the Authority to hold an information session with a relevant person, where a preference for no contact has been registered by a relevant parent.

GDPR means the General Data Protection Regulation (EU) 2016/679.

Identity information is the collective term used in these guidelines to refer to the birth certificate, birth information, early life information, care information, incorrect birth registration information, medical information and provided items as defined in the Birth Information and Tracing Act 2022 and as described in chapter 2.

Illegal birth registration means a situation where a person other than the mother of a person was recorded in the register of births as the mother of the person, and where the person falsely recorded as mother, and where applicable the person recorded as father, treated the person as their lawful child.

Recipient body is the term used to cover both the General Register Office and any "*relevant body*" as defined in the Act. It means a body who is required to process an application for a birth certificate for under Part 2 of the Act. This includes the General Registration Office, the Authority, the Agency and any other body prescribed by the Minister under section 56 of the Act.

Relevant Body is a body to whom an application for records may be made. The Act currently lists the Adoption Authority and the Child and Family Agency as relevant bodies. The Minister can designate by regulation other persons or organisations as relevant bodies to whom an application for information may be made.

Relevant person means any of the following persons:

a) an adopted person
b) a person who is, or suspects they are, the subject of an illegal birth registration
c) a person who was nursed out or boarded out or suspects they may have been nursed out or boarded out
d) a person who does not fall into any of the above categories but who resided as a child in an institution listed in appendix 1.

Tracing body means the two bodies who are authorised by law to deliver a tracing service, namely the Adoption Authority of Ireland and the Child and Family Agency, Tusla.

Parent means the people who were at the time of a relevant person's birth their parent.

Information session means a communication between the relevant person and a suitably trained *designated person*. A session will be required where there is an application for a birth certificate or birth information and a parent named within the birth information has registered a preference for no contact. The information session can be held by means of a short phone call or in person, depending on the preference of the applicant. The content of an information session will encompass:

- the entitlement of the relevant person to obtain, in accordance with the Act, their birth certificate or birth information, and
- the fact that the parent concerned has stated, in accordance with this Act, that he or she is not willing to be contacted by the relevant person and that, in doing so, the parent is exercising their right to privacy.

Once this information session has taken place, the Authority will be notified and will record the fact in the Contact Preference Register to ensure that only one information session will take place for a relevant person.

The information session is given its legislative basis under Section 17(2) of the Act.

Supportive meeting means the meeting that takes place between a *designated person* and a relevant person aged 16 or 17 years in order to provide the young relevant person with requested information. This meeting can be held in person, or by phone or video call and the relevant person can choose to have a person accompany them. The records and provided items will be provided to the relevant person during or after that meeting.

The supportive meeting is given its legislative basis under Section 18 of the Act.

2. Application for Information

2.1. Introduction

2.1.1. Purpose and Principles

The Birth Information and Tracing Act 2022 enshrines in law the importance of a person knowing their origins. The legislation provides for the full release of *identity information* to all relevant persons aged 16 years or over, as well as to next of kin and children of relevant persons in certain circumstances. *Identity information* includes *birth certificates*, *birth information*, *early life information, care information*, *incorrect birth registration information* and *medical information* as defined in the legislation and outlined below on page 9.

This chapter of the guidelines outlines the process for a relevant person, their children or their next of kin to make an application for their *identity information*, and the processes that recipient bodies receiving those applications must follow in administering the application and providing information and records.

In managing applications for the release of information and records under the Act, recipient bodies are asked to adhere to the following important guiding principles:

Principles

1. **Presumption of Validity:** A recipient body should consider that persons applying for access to their identity information have a legitimate belief that there is identity information held by the recipient body.

2. **Supportive approach:** Where requested, the person applying will be supported in their application, the receipt of their identity information and in relation to any further services for which they may be eligible and which may usefully be signposted.

3. **Active communications:** The recipient body will aim to progress each application in a timely manner in accordance with statutory timeframes, and where a delay is experienced or expected, the recipient body will actively engage with the person to keep them informed.

4. **Release of information:** In line with the spirit of the legislation, every effort should be made to provide access to the requested identity information, as well as to other information, the disclosure of which is not prohibited by law, and which could benefit the person in understanding their birth origin story.

2.1.2. Legislative Basis

The guidelines in this Chapter are made under Section 19, 25 and 31 of the Birth Information and Tracing Act 2022. This chapter of the guidelines relates to the operation of Parts 2, 3 and 4 of the Act.

2.2. Who can make an application

An application can be made by a relevant person. It can also be made by a child or a next of kin of a deceased relevant person in certain circumstances as explained below.

2.2.1. Relevant Person

The four categories of person referred to as a "relevant person" are:

a) an adopted person
b) a person who is, or suspects they are, the subject of an *illegal birth registration*,
c) a person who was nursed out or boarded out or suspects they may have been nursed out or boarded out
d) a person who does not fall into any of the above categories but who resided as a child in an institution listed in appendix 1.

2.2.2. Child of a Deceased Relevant Person

Where a relevant person is now deceased, their son or daughter (termed a "qualifying person" in the legislation) will have the same right to apply for information that relates to their parent, as long as the relevant person's parents are also deceased. In other words, they can receive the same suite of, birth, early life, care, incorrect birth registration and medical information that their parent (the relevant person) would have been entitled to receive[1] .

2.2.3. Next of Kin

In circumstances where a relevant person died as a child while they were resident in one of the institutions listed in Appendix 1, a next of kin of that relevant person (termed a "qualifying relative" in the legislation) may apply for the relevant person's *identity information* under the Act.

For the purposes of an application, "next of kin" firstly means a deceased relevant person's mother or father.

If the deceased relevant person's parents are deceased, then the relevant person's brother(s) or sister(s) are considered to be their next of kin.

If the relevant person's parents and siblings (if any) are deceased, then the relevant person's uncle or aunt are considered to be their next of kin.

If the relevant person's parents, siblings (if any), and aunts and uncles (if any) are deceased, then the relevant person's niece(s) or nephew(s) are considered to be their next of kin.

To make an application as the child or next of kin of a deceased relevant person, a person must be at least 18 years of age.

[1] Provisions in relation to qualifying persons and qualifying relatives do not explicitly include the birth certificate but do include birth information which encompasses all of the information contained on a birth certificate.

2.3. Application by a Relevant Person over 18 years

2.3.1. Making an Application

Any relevant person may apply for their own *identity information* that they believe may be held by a *recipient body*.

In the case where a person believes that more than one *recipient body* holds *identity information*, an application should be submitted to each of the relevant recipient bodies. It is the statutory responsibility of each *recipient body* to respond directly to an application made to it. The legislation lists the General Register Office, the *Authority* and the *Agency* as recipient bodies, and enables the Minister to name other bodies. The guidelines will be updated to include any such additions.

Where an application is being made for *identity information* it can only be made by the person to whom that *identity information* relates, except in certain circumstances, see Next of Kin, above.

It is accepted that a person making an application may need help in completing the form. However, it is important that the application is made and signed by the person who is seeking access to their *identity information*, i.e. the relevant person. It will be this person who the *recipient body* will engage with and provide *identity information* to.

2.3.1.1. Available Supports

In line with the principle of a Supportive Approach, the Authority can be contacted on 01 2309 300 and the Agency can be contacted on 0818 44 55 00 to assist an applicant in completing their application.

2.3.1.2. Types of Information

The Birth Information and Tracing Act allows for the release of a wide range of *identity information*. On the application form (see Appendix 2), you will see eight categories of information that can be requested by a relevant person. A relevant person may apply for any combination of categories, or simply tick the box marked [All Information] to request all categories of information.

The types of *identity information* fall into the following categories, and are described in detail below:

I. Birth Certificate
II. Birth information
III. Early life information
IV. Care information (for those who were in a care arrangement)
V. Medical information
VI. Medical information relating to genetic relative
VII. Provided items
VIII. Incorrect birth registration information

Where information falling into any of the above eight categories is present on a record, it must be released, without exception.

In addition, in all cases, the guiding principle should be to release as much information as is legally permissible. In other words, recipient bodies should not limit the release of information to only the above categories of information where additional information exists and they are not legally prohibited from sharing that information. This is an important element of the policy underpinning the Birth Information and Tracing Act 2022, which is designed to be open and inclusive in approach. What this means in practice is that, where a recipient body finds that an applicant's records contain

early life information over and above the specific categories listed, the recipient body should provide that information to the applicant unless it is prohibited from doing so under the GDPR, the Data Protection Acts, or another law. Such laws should be interpreted within the wider framework of the EU Charter of Fundamental Rights and European Convention on Human Rights.

Recipient bodies should also note that definitions of care information and early life information within the Act were consciously framed to be open-ended and non-exhaustive in nature. This is a further feature of the open and inclusive approach that underpins the legislation.

An application must be accompanied by the relevant ID and supporting documentation as set out in appendix 3.

To obtain medical information relating to a genetic relative, an applicant must include details of a medical practitioner on the application form so that this information can be sent to their chosen medical practitioner. This requirement does not apply in the case of an application under section 30 of the Act by a next of kin for the medical records of a relevant person who died as a child in an institution.

I. Birth Certificate

A relevant person can apply for a full and unredacted copy of their Birth Certificate.

II. Birth information

Birth Information is certain categories of data that can be recorded on the birth register held by the General Registrar's Office. This, therefore, is termed 'birth information' and the legislation allows for the release of the categories of data where it appears on files, in addition to any photographs of parents.

- The date, place, and time of the person's birth.
- The person's sex.
- The person's forename(s) and surname.
- The forename(s), surname, birth surname, address, occupation, date of birth, and where applicable, former surname of the person's mother, and the birth surname of the mother's mother.
- The forename(s), surname, birth surname, address, occupation, date of birth, and where applicable, former surname of the person's father, and the birth surname of the father's mother.
- Photograph of a parent.

III. Early life information

Early life information is information that relates to the period of time from a person's birth to when they reach the age of 18, and can include:

- Where he or she lived, and for what dates.
- The date and place of their baptism or any other similar religious or spiritual ceremony performed in respect of him or her.
- A baptismal certificate or equivalent document
- An entry in a baptismal register or equivalent document
- Their birth weight.
- A photograph or image of them
- Information on their health, physical or emotional development.
- Information on any medical treatments, procedures or vaccinations.
- Information on how long their birth mother remained with them in the same place of residence.
- Information on whether the person and their birth mother left their first place of residence (e.g. Mother and Baby Home Institution) separately or together.
- Information on visits, communications, or inquiries by relatives or others.
- Information on whether arrangements were made for an adoption, including the name of the person who made the arrangement.
- Information on whether an adoption took place, including the name of each adoptive parent
- Information on whether the person has a birth relative, whether living or deceased and, in the case of a birth sibling, the sex of that birth sibling and whether they are older or younger.

IV. Care information (for those who were in a care arrangement)

Care information is for relevant persons who were part of a care arrangement and can include:

- The name of a person who cared for the relevant person as part of a care arrangement. This could include:
  - The name of a person in charge of an institution or part of an institution;
  - The name of a person to whom a person was boarded out or nursed out;
  - The name of foster care parents who fostered a child before they were adopted.
- The location where that care was provided;
- The duration for which the person was cared for at a given location;
- The name of any person who made arrangements for the relevant person to be nursed out or boarded out, fostered prior to their adoption or resident in an institution.

V. Medical information

Medical Information includes any information relating to a person's own medical history.

VI. Medical information relating to genetic relative-

Medical information relating to a genetic relative includes the medical history of their relevant parent or genetic relative. **This information is only provided in cases where the information involves a genetic or heredity medical condition that is relevant for the maintenance of the relevant person's health.** For more information, see Chapter 3.

VII. Provided items

"Provided item" includes any item held by the Agency or the Authority, which was provided by a relevant parent, carer or other family member for the purpose of being made available to the relevant person on request. The item could be a letter, photograph, memento or other document or object. It could have been provided historically or could be an item, which was lodged through the statutory Contact Preference Register.

2.3.2. Processing an Application

2.3.2.1. Receipt and Registration of Application

On receipt of an application, a *recipient body* shall log the application and assign a reference code or number to each application received.

A *recipient body* shall acknowledge the receipt of an application within 5 working days, and include the reference code or number for use during follow up engagement.

Where an application is deemed to be incomplete or further information is required by the *recipient body* to progress the application, in line with the principle of **Active Communications,** the *recipient body* shall contact the person and advise on requirements. It may be the case that the application cannot be progressed until the necessary information is received. The *recipient body* should, in line with principles of a **Supportive Approach,** assist the person in this regard to the extent possible.

Once a complete application has been received and logged, the statutory timeline of 30 days begins (see 2.3.2.3 below)

2.3.2.2. Record Search

Following the receipt of a complete application, recipient bodies shall conduct a search for the requested records. It should be noted that all information requested may not be available in every case, but the *recipient body* should make every reasonable effort to locate any information that exists. Recipient bodies should keep in mind the principle of **Presumption of Validity** during this process.

Where a *recipient body* does not hold any of the requested birth information, they shall write to the applicant to inform them of this fact, and also inform the applicant of their right to apply for a Tracing Service and their right to apply to the Contact Preference Register, as appropriate.

In accordance with the principle of **Release of Information**, any other personal information located that is not lawfully prohibited from release should be gathered during this search.

Recipient bodies should ensure that a robust process is in place to process applications fairly in accordance with chronological date of receipt and should endeavour to respond to all applications in accordance with the statutory timeframe set down in the Act.

2.3.2.3. Statutory Timeframes

Under Section 19 of the Act, a *recipient body* must respond to an application for a birth certificate, birth, early life or care information, incorrect birth registration information or a person's own medical information **within one month of the receipt of a complete application**, either by providing the records requested or, where no records are present, by informing the applicant of that fact.

Where a *recipient body* cannot respond within one month, due to the complexity of the case or nature of the information being sought, in line with the principle of **Active Communications,** the body must inform the applicant of the delay within one month. In these cases, the timeframe for final provision of information extends to three months. Communication with the applicant should include the final 3 month deadline for release.

The statutory timeframe does not extend to the medical information of a genetic relative due to the special safeguards which must be applied, although recipient bodies are asked to still adhere to this timeframe to the greatest extent possible when processing applications for third party medical information.

2.3.2.4. Additional considerations for release of Birth Certificate, Birth Information, and Medical Information relating to Genetic Relatives

Where an applicant is seeking access to their birth certificate or birth information (Categories I and II of *identity information*), the *relevant body* must follow the process set out under sections 2.3.2.5 and 2.3.2.6 below.

Where an applicant is seeking Medical Information relating to Genetic Relatives (Category VI of *identity information)*, additional guidelines apply due to the special nature of the information. These guidelines appear in full in Chapter 3. In summary:

- the information will be released via a medical practitioner;
- only information that is relevant to the maintenance or management of the person's health, i.e. a genetic or hereditary medical condition, will be released;
- the name of the genetic relative will not be released; and
- the relationship of the genetic relative to the relevant person will not be disclosed.

In all other cases, the *relevant body* can immediately proceed to release the information in accordance with the procedure outlined under the heading "Provision of Records" below.

2.3.2.5. Check the Contact Preference Register for a parent's Contact Preference.

Where a *recipient body* receives an application for a birth certificate or birth information and where it holds such data, it must contact the Authority in order to establish whether there is a no contact preference recorded for the parent. It should do this by compiling the applications received that working day and the recipient body's single point of contact should email the Authority at the following dedicated email addresses, tusla@aai.gov.ie or GRO@aai.gov.ie as appropriate. To allow the Contact Preference Register to be checked, the recipient should provide the following information: (1) Name of Applicant; (2) Names of each parent listed on the birth certificate/ birth information; (3) where available, date of birth or address of each parent listed on the birth certificate/ birth information;. The Authority then has three working days to reply to the recipient body's point of contact.

Where the *recipient body* is aware that a parent is deceased, contact with the Authority is not required and the *recipient body* can immediately proceed to release the records to the applicant in accordance with subsection "Provision of Records" below.

The Authority shall check the register and advise the *recipient body* if:

a) A parent has not made any entry on the register.
b) A parent has expressed a preference for contact or is willing to have contact.
c) A parent has expressed a preference for no contact and an information session has been held.
d) A parent is deceased.
e) A parent has expressed a preference for no contact and no information session has been held.

Where any of (a) – (d) apply in the case of each parent who is named on the birth certificate or birth information, the *recipient body* may proceed to issue the information in accordance with subsection "Provision of Records" below.

Where there is no entry on the register or there is a preference for contact (i.e. category (a) or (b) above applies), the *recipient body* will communicate this fact in the statement when providing the birth certificate or information to the applicant (See Appendix 5).

If a preference for no contact is registered by a relevant parent and no information session is recorded on the contact preference register (category (e)), then the person will be informed by the Authority of the requirement to attend an information session with a *designated person* as detailed in Section 2.3.2.6 below. The *recipient body* may provide the Authority with contact details for the applicant for this purpose.

2.3.2.6. Information Session

The information session is a necessary mechanism to ensure the release of information to a relevant person whilst also safeguarding the privacy rights of a relevant parent.

The Authority may designate persons or classes of persons to conduct an information session. This designation can include persons employed or contracted by the Agency.

At the session, the applicant will be informed by the *designated person* of their entitlement to receive their birth certificate and information, and that their parent has engaged their right to privacy and does not wish to have contact.

In accordance with the principles of a **Supportive Approach** and **Active Communication**, the information session will be conducted sensitively and respectfully, acknowledging the rights and wishes of all parties.

The information session may be held by means of a short phone or video call or may be held in person, depending on the preference of the relevant person.

Once the information session has taken place, the *designated person* will confirm this in writing to the *recipient body* and to the Authority.

On receipt of this written confirmation, the body will then release the record or records to the applicant and may issue a statement alongside the records setting out further details of the records being released.

Confirmation that the information session has taken place will also be recorded on the contact preference register, to ensure that a person will only be required to attend one information session regardless of the number of applications made.

2.3.2.7. Provision of Records

Where a *recipient body* has received an application for information and has followed the steps laid out in the preceding sections as required, the body will prepare the information and records gathered for release.

This information will be supplied to the person by providing copies of the records in which the information is contained, except for Medical Information of a Genetic Relative (see Chapter 3), which will be provided via a GP.

In accordance with feedback provided through stakeholder engagement, where an excerpt from a record is being released such as a single entry from a page of an admissions register, the entries

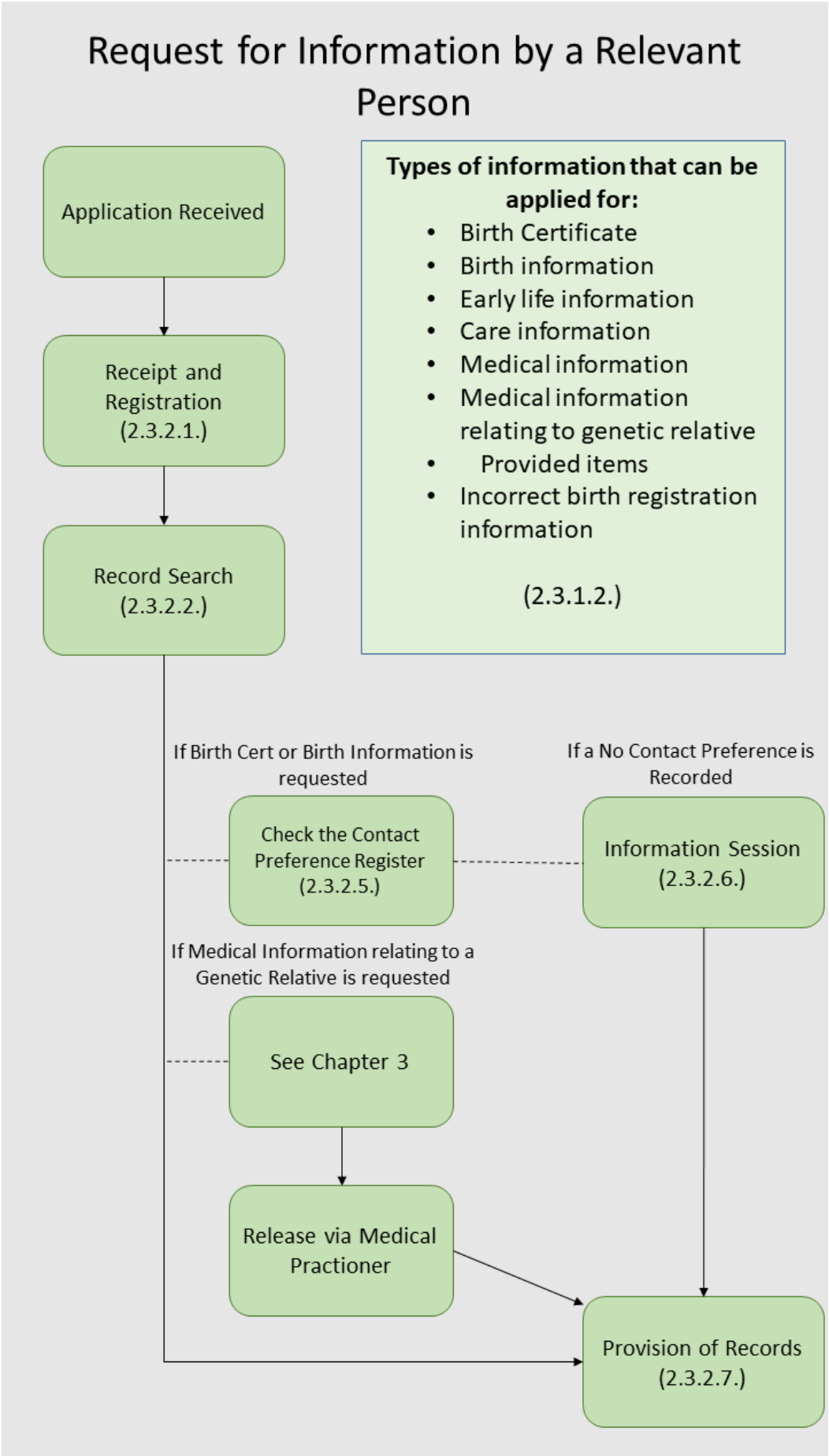
relating to other data subjects should be removed in such a way that it is clear that these are the records of entirely separate data subjects, i.e. other former residents. People who have received records under *GDPR* have advised that some current practices whereby this information is removed and referred to it as 'third party information' has left them thinking that the removed information relates to their mother or other family member and is being denied to them.

A statement may be issued to accompany the records. This statement should include information which would help the applicant understand the records presented to them, in accordance with the principle of a **supportive approach.** The statement should also highlight upfront anything which may be beneficial for the applicant to be aware of in advance. This could include, for example, the use of language on historical records which would be considered insensitive or offensive today (See Appendix 5).

If requested, the Agency or the Authority can also provide additional support and guidance to the person in the interpretation of the records.

Once information has been released to the applicant, the case may be closed.

Request for Information by a Relevant Person



2.4. Application by a Relevant Person aged 16 or 17

2.4.1. Making an Application

The process for making an application as a *relevant person* aged 16 or 17 years is the same as that detailed under 2.3.1. above, except that a *relevant person* aged 16 or 17 must make their application via the Child and Family Agency only.

The category of incorrect birth information is not applicable to a *relevant person* aged 16 or 17 years. This is due to the fact that the category "incorrect birth information" is responding to an issue associated with the legacy of previous adoption practice and culture.

The *Agency* will lead the management of applications from young people on behalf of the *Authority* which has overall responsibility in the legislation.

2.4.2. Processing an Application

The processing of an application made by a *relevant person* aged 16 or 17 is the same as that detailed under 2.3.2. above, except where noted below.

2.4.2.1. Record Search

Following the receipt of a complete application, the Agency will conduct a search for the requested records. In doing so, it will liaise with the Authority on search and retrieval of records. A data sharing agreement should be in place to underpin this process.

It should be noted that, while all information requested may not be available in every case, every reasonable effort should be made to locate any information that exists. Recipient bodies should keep in mind the principle of **Presumption of Validity** during this process.

In accordance with the principle of **Release of Information**, any other personal information located that is not lawfully prohibited from release should be gathered during this search.

2.4.2.2. Supportive Meeting and Provision of Records

Where the Agency has received an application for information, and has followed the steps laid out in the sections 2.3.2.1.-2.3.2.6., it will prepare the information and records gathered for release.

Following this, the Agency, on behalf of the Authority, will ensure the release of the information through or following a supportive meeting between the person and a *designated person*.

Where an information session is required, this may take place at the same time as the supportive meeting.

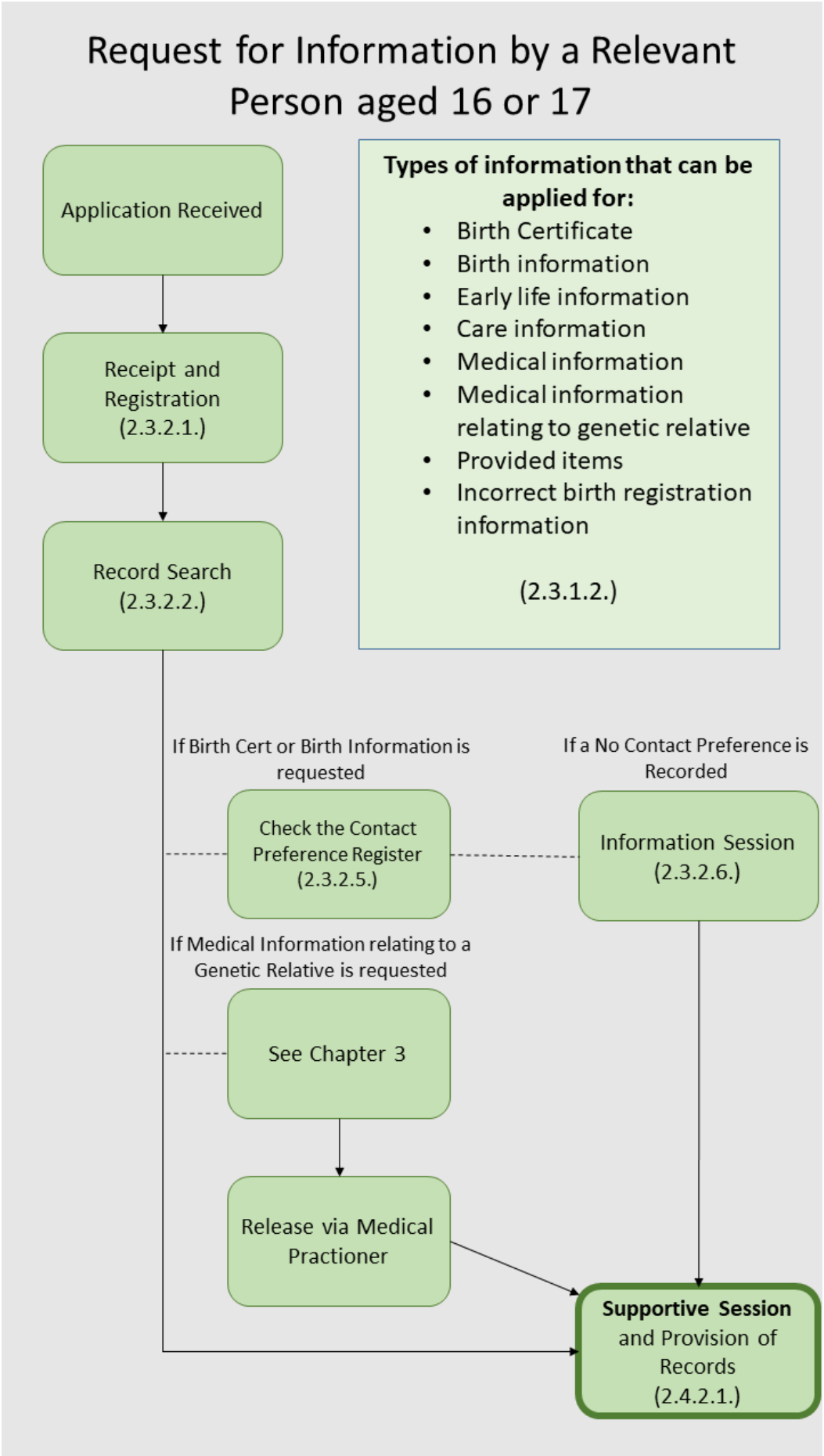
This supportive meeting can take place in person or by phone or video call, and the person may bring someone of their choosing with them for support. This mechanism is designed to ensure that there is an additional layer of support available to these younger applicants at the point of receiving and assimilating the information, as well as thereafter.

The young person will then be supplied with copies of the records in which the information is contained. A statement should be issued to accompany the records. This statement should include information that would help the applicant understand the records presented to them, in accordance with the principle of a **supportive approach.**

If requested, the Authority can also provide additional support and guidance to the person in the interpretation of the records and assimilation of the information.

Once information has been released to the applicant, the case may be closed.

Request for Information by a Relevant Person aged 16 or 17



2.5. Application by a Child of a deceased Relevant Person

2.5.1. Making an Application

The Birth Information and Tracing Act 2022 enshrines in law the importance of a person knowing their origins. This includes a child, whose now deceased parent was adopted, nursed out, boarded out or subject to an *illegal birth registration*, being able to access information on their parent's origins as a shared element of their own origins.

A child of a deceased relevant person is termed a "*qualifying person"* in the legislation. A qualifying person aged 18 years and over may make an application for their deceased parent's *identity information* to any *relevant body*. The process for making an application as a *qualifying person* is the same as that detailed under 2.3.1. above. The one distinction is that the legislation does not provide for a qualifying person to apply for their parent's birth certificate as a distinct category. This is because the qualifying person can apply for birth information which will encompass the deceased parent's birth certificate where it is held by a *relevant body*.

2.5.2. Processing an Application

The processing of an application made by a *qualifying person* is the same as that detailed under 2.3.2. above, except where noted below.

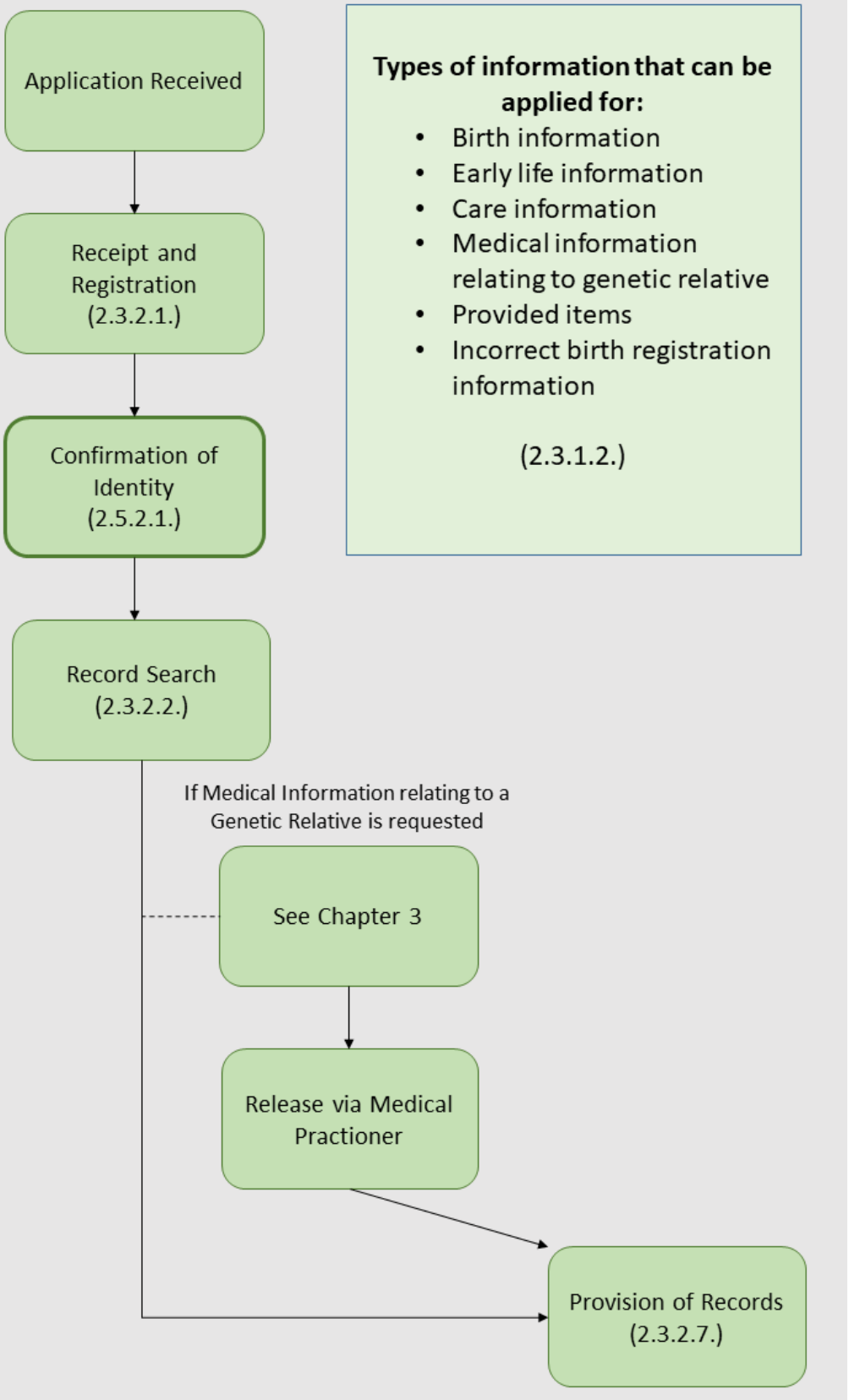
2.5.2.1. Confirmation of Identity

Prior to the release of records, the *relevant body* must be satisfied that the applicant is a qualifying person under the Act.

2.5.2.2. Provision of Records

For all applications from a qualifying person, the relevant person and their parents are deceased so there is no need to search the contact preference register or undertake an information session. The *relevant body* may proceed directly to the provision of information.

Request for Information by the child of a deceased Relevant Person



2.6. Application by Next of Kin of a deceased Relevant Person

2.6.1. Making an Application

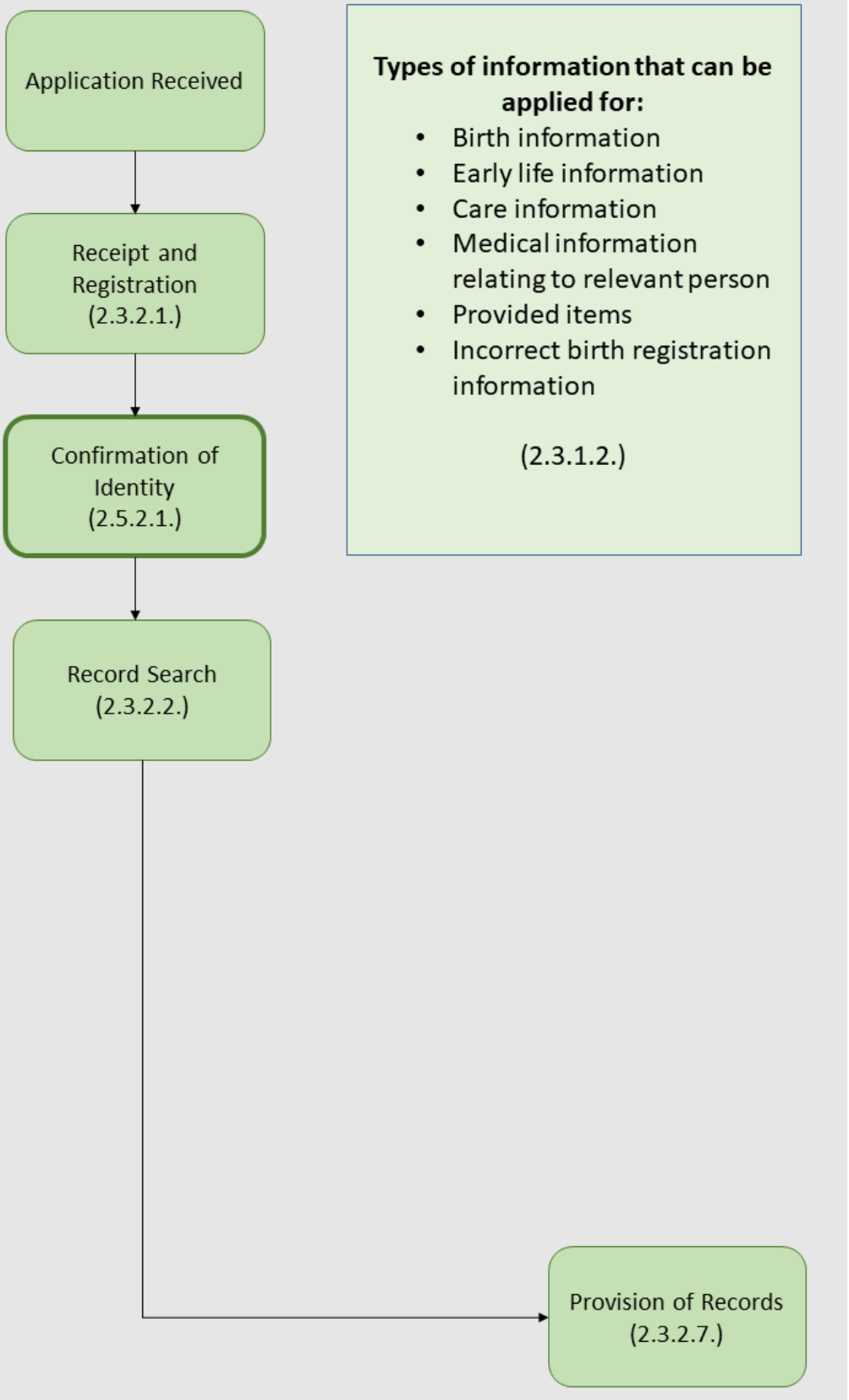
The process for the next-of-kin of a deceased relevant person (a "qualifying relative") to make an application is the same as that detailed under 2.3.1. above. The one distinction is that the legislation does not provide for a qualifying relative to apply for their parent's birth certificate as a distinct category. This is because the qualifying relative can apply for birth information which will encompass the deceased relevant person's birth certificate where it is held by a *relevant body*.

2.6.2. Processing an Application

2.6.2.1. Confirmation of Identity

Prior to the release of records, the *relevant body* must be satisfied that the applicant is a qualifying relative under the Act.

Request for Information by the next of kin of a deceased Relevant Person



2.7 Review and complaints process

All relevant bodies should have in place processes for applicants to request a review of the information released under the Birth Information and Tracing Act 2022, as well as a complaints process which is available to applicants.

Where an applicant is dissatisfied with the material which has been provided to them following an application for information, they may request a review of the case. In these cases, a review officer, who may be a line manager of the person who released the records, or other officer appointed for the purpose of reviewing such cases, should review the case. Where the officer concludes that additional material should have been released to the requestor, this shall be released. Where the review officer is satisfied that all information available for release was provided, the requester will be informed of this conclusion.

Relevant bodies should have complaints procedures in place for individuals who wish to make a complaint about the actions of the *relevant body*. In the case of the Agency and the Authority people who wish to make a complaint may be directed to:

https://www.aai.gov.ie/en/customer-information.html

https://www.tusla.ie/about/feedback-and-complaints/

For any individual who is dissatisfied with the result of the complaints process within an organisation, they may be directed to the Ombudsman: https://www.ombudsman.ie/making-a-complaint/make-a-complaint/

Note: the Ombudsman is clear that they will only consider a complaint against a body where the individual making a complaint has attempted to resolve the issue directly with the body concerned. They will not hear complaints at first instance.

3. Release of Medical Information of a Genetic Relative

3.1. Introduction

The Birth Information and Tracing Act 2022 enshrines in law the importance of a person knowing his or her origins. Included in this is the ability for relevant persons and qualifying persons to obtain information on the medical history of their relevant parent or genetic relative where it relates specifically to a genetic condition. The Act requires that, where medical information of a genetic relative relating to an applicant exists in a *relevant body*'s files, and its release would likely have a substantial benefit to the maintenance of the applicant's health, the *relevant body* would release it to the applicant's nominated medical practitioner in a non-identifying format. This chapter explains exactly what information qualifies for release in this regard and the manner in which it should be identified and released.

The Birth Information and Tracing Act presents a very significant change in access to third party medical information. It provides for an adopted person to have a legal right to the medical information of somebody else. Providing an individual with access to third party medical information is a significant legal right that requires careful consideration and safeguards. The following chapter takes this into account and provides for the efficient and secure handling of sensitive information.

It is important to note that third party medical information will be released through a certified medical practitioner. For the purposes of the Act, a medial practitioner is defined as:

"A medical practitioner who is for the time being registered in the register of medical practitioners established under section 43 of the Medical Practitioners Act 2007."

It includes General Practitioners (GPs), specialised consultants and other medical doctors. This also includes a medical practitioner overseas who is currently registered under professional regulation legislation equivalent to the *Medical Practitioners Act 2007,* such as the Medical Act 1983 in the United Kingdom and the Health Practitioner Regulation National Law Act 2009 in Australia. Further information regarding the definition and regulation of medical practitioners can be found in Section 3.10 of these guidelines.

This chapter, which should be read in conjunction with chapter 2, outlines the relevant criteria and steps necessary to facilitate the provision of medical information of a genetic relative as outlined in Section 16 of the Birth Information and Tracing Act 2022. These include the purpose of making an application, the categories of information which can be obtained, the safeguarding of the privacy of all parties during the process, the application search process and the release of information to the applicant.

It should be noted that this chapter does not apply to qualifying relatives who can receive medical information relating to their deceased relative directly but cannot apply for other third party medical information. It also does not apply to any third party medical information which is shared through the Contact Preference Register because any such information is being voluntarily provided by a person for the explicit and express purpose of providing this directly to another specified person.

3.2. Purpose of Making an Application for Information

The purpose of making an Application for Information is to enable a relevant person or a qualifying person to obtain information relating to medical history of his or her relevant parent or genetic

relative. This is limited to information on genetic or hereditary medical conditions as these could be relevant for the maintenance of the applicant's own health or of another person related to them.

The medical practitioner will be provided with a statement setting out any relevant third party medical information contained in files found during the Search Process laid out in Section 3.7 of these guidelines. The medical practitioner can then convey and discuss this information with the applicant.

Any relevant third party medical information will be any information that meets the criteria of categories of information laid out in Section 3.3 below.

3.3. Categories of Information

The categories of medical information relating to a genetic relative which may be released on application encompass diseases, syndromes, or medical conditions believed to be genetically transmissible. A non-exhaustive list of these diseases, syndromes and medical conditions will be published alongside these guidelines. Where a file contains the fact of one of these diseases, syndromes or conditions, that information should be released in accordance with the requirements set out in these guidelines. Where a file lists a disease, syndromes or condition which is not stipulated in this list but which a relevant body considers may be genetically transmissible, the relevant body may contact DCEDIY to obtain expert guidance on this matter (see subsection 3.8 below).

It should be noted that files obtained during the search procedure outlined in Section 3.7 may or may not contain information relating to the above categories. As stated previously, applicants should be informed of the information that is available from files found during this search process via the Medical Information Statement provided to their nominated medical practitioner. Applicants should be notified by a *relevant body* that a Medical Information Statement has been provided to their nominated medical practitioner for the applicant to receive. Where no such information is found, the applicant should be informed of this directly so that they know not to expect a Medical Information Statement to be provided to their nominated medical practitioner.

3.4. Categories of Genetic Relative

A relevant person's "genetic relative" is defined in the Birth Information and Tracing Act 2022 as:

- His or her mother or father;
- A child or parent of his or her mother or father;
- A sibling, uncle, aunt or first-cousin of his or her mother or father, whether the relationship is of the whole blood or half blood;
- A person to whom, but for the adoption of any person, the above would apply.

Medical information found during searches conducted under the procedures outlined in Section 3.7 should be limited to information relating to genetic relatives only. Measures for ensuring the protection of any personal data of those persons contained on files found during the search process is outlined in the Section 3.5 below.

3.5. Safeguarding of Privacy

Due to the sensitive nature of the information being processed by relevant bodies during the search procedure, there are safeguards within the legislation where it relates to the medical information of genetic relatives. As per section 15 (6) of the Birth Information and Tracing Act 2022, only the following records are within scope for the search process:

(a) records relating to the adoption of a person,

(b) records relating to a care arrangement, or

(c) records created or held by a registered adoption society or an institution specified in the Schedule.

A relevant person who has attained the age of 16 years or a qualifying person may apply in writing to a *relevant body* for the provision by the *relevant body* to him or her of medical information that—

(a) is contained in the categories of records listed above,

(b) relates to his or her genetic relative, and

(c) is relevant to the health of the relevant person or qualifying person.

Finally, there are a number of steps which must be taken to ensure information is properly processed in accordance with the Act, namely:

- The information will be released via a medical practitioner;
- Only information that is relevant to the maintenance or management of the person's health, i.e. a genetic medical condition, will be released;
- The name of the person to whom the record relates will not be released;
- The relationship to the relevant person will not be disclosed.

A sample cover letter which will be issued by the *relevant body* to the applicant's nominated medical practitioner can be found in Appendix 5 of these guidelines.

3.6. Making an Application for Information

Applications for information should be made under the process outlined in Chapter 2 of these guidelines.

3.7. Undertaking the Search Process

Relevant bodies should identify and search the specific records which fall within the scope of the search process for any third party medical information as explained in section 3.5. Any such information within the records should be extracted and incorporated into a Medical Information Statement in a non-identifying manner. It should be noted that the *relevant body* may not be able to stand over the validity of records, and this should be reflected on the Medical Information Statement if this is the case. This statement is discussed in more detail in Section 3.9. This statement will then be passed to the nominated medical practitioner for release to the applicant under Section 3.10. A sample letter, which is to be released to the applicant in the event of no information being found by the *relevant body*, is set out in Appendix 5 of these guidelines.

3.8. Central Support for Relevant Body during Search Process

In order to ensure that relevant bodies are able to conduct thorough searches while ensuring the aforementioned safeguards are adhered to, support for queries will be provided by DCEDIY. During the search and retrieval process, the *relevant body* may not be able to make a decision to release without guidance from a qualified medical professional as to whether the disease or condition in question is genetic or hereditary in nature. In these cases only, relevant bodies may submit queries to DCEDIY Adoption Policy Unit who will obtain expert guidance on the specific query. Each query will be logged and a record of questions asked and decisions made will be kept to ensure that these guidelines can be updated to take account of the expert medical decisions reached. This will support consistency and efficiency of decision making over time.

3.9. Compilation of Medical Information Statement

A key stage of the process is the compilation of the Medical Information Statement by the *relevant body* which will be provided to an applicant's nominated medical practitioner. This statement is intended to provide the applicant with non-identifying information on genetic medical conditions which may be part of their genetic family medical history. The applicant will not receive a copy of records, and all information which is able to be released will be placed on the Medical Information Statement.

As stated previously, there are a number of safeguards in place to ensure that only necessary medical information is provided and no identifying information is included during the creation and dissemination of the statement.

The compilation of the statement itself is a relatively straightforward process. Medical information relating to genetic relatives on institutional or adoption records is identified during the initial search. When the search is complete and all information has been noted, this information in its entirety, save for the safeguards outlined above, should be placed on the statement which is to be provided to the applicant's medical practitioner. It should be noted that once information is identified as relating to a genetic condition, the material is to be released without knowing anything about the medical history of the applicant. The description of medical information should provide the precise wording of the condition minus any identifying information. The nominated medical practitioner will be able to discuss medical terminology present on the statement in more detail with the applicant. The Medical Information Statement will then be sent from the *relevant body* to the nominated medical practitioner via the contact information provided by the applicant on their initial application form.

3.10. Release of Information

While statutory timeframes do not apply to this chapter, a *relevant body* shall endeavour to issue a Medical Information Statement as expeditiously as possible. It is recommended that relevant bodies adhere as closely as possible to the one month deadline as outlined in previous chapters of these guidelines.

Where a *relevant body* is unable to meet this deadline, due to the complexity of the application concerned or the nature of the information sought under the application, it shall endeavour to provide a Medical Information Statement three months after the date on which it receives an application. The

relevant body must convey notice of this extension to the applicant at the time of the extension being made.

As mentioned previously, medical information relating to a genetic relative will be released to a certified medical practitioner. This medical practitioner is defined in the Birth Information and Tracing Act 2022 as:

"A medical practitioner who is for the time being registered in the register of medical practitioners established under section 43 of the Medical Practitioners Act 2007".

The register of medical practitioners can be checked online using a medical practitioner's registration number on the Medical Council of Ireland's website.

It is possible that some applicants may nominate medical practitioners who are either not registered in the State or visiting from an EEA Member State on a temporary basis and are, therefore, practicing under Section 50 of the *Medical Practitioners Act 2007*. The Birth Information and Tracing Act 2022 states that such a person may be nominated by an applicant if they meet the equivalent qualifications to a medical practitioner registered in Ireland under the *Medical Practitioners Act 2007.*This involves being currently registered under equivalent legislation in their home state such as the Medical Act 1983 in the United Kingdom, the Health Practitioner Regulation National Law Act 2009 in Australia, the Health Practitioners Competence Assurance Act 2003 in New Zealand, the various Medical Practitioners Act(s) in the thirteen provinces and territories of Canada, and the separate Medical Practice Act(s) in place for all 50 states in the United States of America. The District of Columbia and the U.S. territories (Puerto Rico, Guam, the Commonwealth of the Northern Mariana Islands, and the U.S. Virgin Islands) each have their own Medical Practice Act for the purposes of registration. This registration status can be checked via the Federation of State Medical Boards in the United States of America. Registration of nominated medical practitioners from the following states can be verified at the below sites:

1) Ireland
2) United Kingdom
3) Australia
4) New Zealand
5) Canada
6) United States

Medical information will be supplied to the applicant by their medical practitioner via the Medical Information Statement outlined in Section 3.9. This ensures that the medical practitioner is in a position to provide additional support and guidance to the person in the interpretation of the Medical Information Statement, as well as guidance on next steps involving the maintenance of their health.

Once information has been released to the applicant, the case may be closed.

3.11. Assistance During and After Application:

See Chapter 2, Section 2.3.1.1. of these guidelines.

4. Application for Tracing

4.1. Introduction

4.1.1. Purpose and Principles

The tracing service aims to help people who would like to make contact or exchange information with a specified person. The service is delivered by the **Child and Family Agency, Tusla** and the **Adoption Authority of Ireland**. Below, these are referred to as *tracing bodies.*

The tracing process involves the Agency or the Authority working to locate a specified person at the request of an applicant, with the aim of supporting consensual contact or sharing of information.

In addition to supporting those who would like contact with a relative, the service can be a powerful way for people to gain deeper insights into their family origins, particularly given the often limited information available on historic files.

In managing applications for the tracing service, tracing bodies are asked to adhere to the following important guiding principles:

Principles

1. **Supportive Approach:** The person applying will be supported in their application, and where requested, will be informed of any further services for which they may be eligible and which may usefully be signposted.
2. **Active Communications:** The tracing body will aim to progress each application in a timely manner, and where a delay is experienced or expected, the tracing body will actively engage with the person to keep them informed.

4.1.2. Legislative Basis

The guidelines in this Chapter are made under *Section 37* of the Birth Information and Tracing Act 2022, and pertain to the provisions in Part 5 of the legislation.

4.2. Who Can Make an Application

An application for the tracing service can be made by:

- A relevant person
- A birth relative of a relevant person, i.e. a parent, grandparent, aunt/uncle, sibling, or cousin.
- A relative of a relevant person, i.e. a parent, grandparent, aunt/uncle, sibling, or cousin, by way of their adoptive parent(s)
- An adoptive parent of an adopted child under the age of 18 may make a tracing application on their behalf for the purposes of requesting information only. Where an application is made on behalf of a person under the age of 18 by their adoptive parent, it is essential that the views of the child or young person are taken into consideration by the body conducting the trace, and that appropriate supports are put into place to ensure that any information is communicated to the child or young person sensitively and compassionately.

A relevant person is defined in the Act and in these guidelines as:

a. an adopted person
b. a person who is, or suspects they are, the subject of an *illegal birth registration*,
c. a person who was nursed out or boarded out or suspects they may have been nursed out or boarded out
d. a person who does not fall into any of the above categories but who resided as a child in an institution listed in appendix 1.

4.3. Who can be the Subject of a Trace

A relevant person can apply for a trace in relation to their:

a. parent
b. grandparent,
c. aunts and/or uncles,
d. siblings
e. cousins.

Here, "parent" includes the adoptive parent of a person. Sibling, aunt, uncle and cousin relationships include relationships of half-blood, full blood, and by marriage.

The people listed above can similarly apply for a trace in respect of the relevant person concerned.

4.4. Application for Tracing in Ireland

4.4.1. Making an Application

A person can apply to the Agency for a tracing service through the bespoke website for information and tracing services, www.birthinfo.ie or by post to the Agency.

A phone line will also be available for persons who wish to have a paper application posted out or who need assistance with an application.

An application for a tracing service shall be made to the Agency in the specified form and shall be accompanied by appropriate photographic ID.

Once an application has been received by the Agency, in order to provide the most effective service to the applicant, the Agency may refer an application to the Authority, in accordance with a mutually agreed tracing case assignment protocol, for delivery by the Authority of a tracing service. In general terms, the following shall be the case:

i. Where the Agency holds the records (or the majority of the records) in respect of the individual, it shall provide the tracing service.
ii. Where the Authority holds the records (or the majority of the records) in respect of the individual, it shall provide the tracing service.
iii. In cases where it may not be clear as to what records exist and where records (or the majority of records) are held, the Agency shall provide the tracing service.
iv. Where an applicant indicates that they would like the service to be provided by one particular body, this shall be facilitated where possible.

In some cases, an applicant may not know the name of the agency involved in an adoption and, so, a crucial initial step will involve the sharing of information between the Agency and the Authority to seek to establish which agency was involved and where the majority of the records may be held.

In all cases, the applicant will be informed of the *tracing body* (the Agency or Authority, as appropriate) providing the service. This can communicated as part of the acknowledgment at 4.4.2. below.

When an application has been transferred from the Agency to the Authority, the Authority is then the responsible *tracing body* for progressing and closing the case in accordance with the steps below.

4.4.2. Processing the Application

4.4.2.1. Review the Application Form and Check ID

On receipt of an application, the *tracing body* must check the accompanying ID. Acceptable forms of ID are listed in Appendix 2. In line the with principle of **presumption of validity** the *tracing body* shall assume good faith on the part of the applicant and advise any applicant without the appropriate proof of identity on which forms of identification are acceptable.

Where an application is deemed to be incomplete or further information is required by the *tracing body* to progress the application, in line with the principle of **Active Communications** the *tracing body* shall contact the person and advise on requirements. It may be the case that the application cannot be progressed until the necessary information is received. The *tracing body* should, in line with principles of a **Supportive Approach**, assist the person in this regard to the extent possible.

4.4.2.2. Receipt and Registration of Application

On receipt of a complete application, a *tracing body* shall log the application and assign a reference code or number to each application received.

A *tracing body* shall acknowledge the receipt of an application within 5 working days, and include the reference code(s) or number(s) for use during follow up engagement.

In addition, the *tracing body* shall inform the applicant of their right to make an application for an entry in the Contact Preference Register maintained by the Authority.

4.4.2.3. Search and Retrieval of Records

Where, in accordance with the tracing case assignment protocol, the application is referred to the Authority, the Agency shall also provide copies of any records relating to the application or shall confirm if records require to be sourced and shared. Similarly, where the Agency retains an application but some records relevant to the application are held by the Authority, the latter shall source and share copies of these records with the Agency, on request, for the purpose of supporting the Agency to deliver a tracing service. Section 34(7) of the legislation provides that *"The Agency and the Authority shall each provide the other body with such information as is necessary for the performance by the other body of its functions under this section".*

In all cases, the *tracing body* responsible for the application shall search and retrieve records relevant to the case. The *tracing body* shall commence the search process by completing the following tasks as appropriate to the particular case:

a. Review the applicant file and double check information received to date
b. Check the Contact Preference Register for any record of a contact preference and up to date contact details.
c. Contact the General Register Office (GRO) and obtain necessary information from birth, death and marriage registers

d. Contact prescribed third parties in accordance with section 34 of the Act to obtain relevant information in respect of the person being traced. Relevant information in this context could include the person's married name, their previous or current address and other contact information.
e. Check the edited Register of Electors

Where necessary for the purposes of conducting the search process, the Authority and the Agency may request and share relevant information with each other.

4.4.2.4. Case Allocation, Prioritisation, and Initial Meeting

The responsible *tracing body* shall review the application and associated records and assign priority in accordance with nationally agreed priority categories. The application shall then be placed on a list in accordance with its assigned priority category and the remaining sections of this document shall apply as appropriate.

Whilst all tracing applications are considered very important, applications may be prioritised by the *tracing body* based on the following categorisation:

- Tier 1- Exceptional Health Circumstances (or other exceptional need)
- Tier 2- Parent/ Child Tracing Request
- Tier 3- Sibling Tracing Request
- Tier 4- Requests based on all other family relationships

Tier 1- Exceptional Health Circumstances (or other exceptional need)

It is acknowledged that, in limited circumstances, some applicants may have an advanced need to prioritise their application for health-related reasons.

Exceptional health circumstances under which a person may be considered for prioritisation may include:

- A terminal illness
- Palliative Care
- Brain health including Dementia/Alzheimer's
- A significant life limiting illness

Should an applicant indicate in their application that they wish to be considered for prioritisation based on exceptional health circumstances, and has provided supporting documentation such as a consultant or GP letter, this shall cause the application to be treated as a 'tier 1' application.

In situations where an applicant has not requested priority based on health circumstances, but a *relevant body* has identified a reason as to why their application should be prioritised as a 'tier 1' application, they may apply discretion in prioritising.

Tiers 2- 4- Relationship-based Categories

All applications which do not qualify under tier 1 may be prioritised based on relationship, and placed on the list referenced in 3.3 in accordance with the following hierarchical categories:

Tier 2- Parent/Child;

Tier 3- Sibling;

Tier 4- All other family relationships.

In applying this approach, the Authority and/or the Agency must satisfy themselves that no application waits longer than 6 months for a pre-trace meeting which marks the beginning of the active tracing process. This process will begin when the case is allocated to the tracing team, who shall:

a. Contact the applicant and invite them to a meeting which can be virtual, face to face or by means of a phone call, as may be appropriate in the circumstances
b. Commence pre-search counselling/support with applicant
c. Decide, in consultation with the applicant, on the direction of the case and sequencing of the search to the extent possible

4.4.2.5. Third Parties from Whom Information can be Requested

Under section 34 of the Birth Information and Tracing Act 2022, the list of persons who must respond to requests from the Agency or the Authority for information for the purposes of conducting a trace includes:

- a Department of State or any other office or body in relation to which functions are vested in the Minister of the Government having charge of that Department of State;
- the Health Service Executive;
- a voluntary maternity hospital providing services under section 38 of the Health Act 1970;
- the Garda National Immigration Bureau;
- An Post;
- a diocese or parish of the Roman Catholic Church;
- a diocese or parish of the Church of Ireland;
- any body subsequently designated by the Minister

Tracing bodies may utilise other available resources such as the publicly available elements of the electoral register, the property registration authority land registers and the 1901 and 1911 census records held by the National Archives. This is not an exhaustive list.

Tracing bodies may also have recourse to publicly available resources which lie outside the jurisdiction such as the General Register Office for England, Scotland, Wales, and Northern Ireland.

4.4.2.6. Support and Assistance

The responsible *tracing body* may provide an applicant with support and assistance in accordance with Section 63 of the Act, where requested by the applicant. This may include assistance in relation to making an application for a tracing service or support in relation to reading and understanding records provided on foot of an application, and support where information or a response provided by a specified person could be potentially distressing to the applicant.

4.5. Contact with a Person Who is the Subject of a Trace

4.5.1. Where a person cannot be located

Where a person cannot be located, having taken all reasonable steps, the *tracing body* will inform the applicant and will close the case. This information is likely to be deeply disappointing for the

applicant and will be conveyed by a suitable person in line with the principle of a **Supportive Approach**.

4.5.2. Where a person is located

Section 35 of the legislation provides that, once a person has been located, the Agency or the Authority shall ascertain (as relevant to the application) whether the specified person is:

a. Willing to have contact with the requester
b. Willing to provide information to the requester
c. Willing to accept information provided by the requester.

An entry on the Contact Preference Register may indicate the following relevant preferences (see 5.1.2. below):

1. A preference for contact
    a. Is seeking contact with a specified person;
    b. Is willing to be contacted by a specified person (this could include being willing to provide information if requested by a specified person);
    c. Is seeking information relating to a specified person;
2. A preference for no contact
    a. Is not willing to have contact of any kind;
    b. Is not willing to have contact with the specified person but is willing to provide information if requested by a specified person.

Where the specified person has made an entry on the Contact Preference Register that is relevant to the application, then the Authority or Agency may take this as an initial indication of their preference in relation to contact following a trace. However, a No Contact preference does not preclude the Agency or the Authority from contacting the person to confirm that their preference is unchanged.

Where no entry on the Contact Preference Register exists, the Authority or Agency will seek to make contact by post or an alternative method appropriate to the circumstances of a particular case. In some cases, this may involve providing a letter to Client Identity Services (Department of Social Protection) to forward to the person being traced.

Where the person has been contacted and responds, they will be invited to a meeting with a social worker which may be virtual, face to face or a phone call, as appropriate.

Where the *tracing body* has made all reasonable efforts to contact the person but there is no response to its communications, the *tracing body* will inform the applicant and will close the case. This information is likely to be deeply disappointing for the applicant and will be conveyed by a suitable person in line with the principle of a **Supportive Approach**.

4.5.2.1. Tracing for the Purpose of Seeking or Sharing Information

Where the person has been traced for the purposes of seeking or sharing information only, the social worker will meet, virtually, face to face or by means of a phone call, with the person to convey the purpose of the trace and establish if the person is willing to share or receive information as appropriate.

Where the person is willing to receive information, this will be provided to them by the social worker, the applicant will be informed of this outcome and both the applicant and the traced person will be informed that the case is closed.

Where the traced person is willing to share information, they will be asked to provide this to the social worker who will transmit it to the applicant. Once the information has been provided to the applicant, the social worker will notify both parties that the case is closed.

Where the person is not willing to receive or share information at this time, as the case may be, the social worker will convey this information to the applicant in line with the principle of a **Supportive Approach** and will close the case.

If a person decides to seek contact following this process, proceed to Section 4.6.2.2.

4.5.2.2. Tracing for the Purpose of Contact

Where the person has been traced for the purposes of contact, the social worker will meet with the person, virtually, face to face or by means of a phone call, to convey the purpose of the trace and establish if the person is willing to have contact with the applicant. Where the person is open to the possibility of contact, the social worker will undertake a social history and assessment, and commence pre-contact counselling/support. The steps in section 4.6.2.3. and 4.6.2.4. will then be undertaken.

Where the person is not agreeable to contact and is satisfied that they do not wish to take further time to reflect on that decision, the social worker will convey this information to the applicant in line with the principle of a **Supportive Approach** and will close the case.

4.5.2.3. Supporting Contact between the Applicant and the Traced Person

In the case of tracing for contact, the social worker shall prepare both parties prior to initial contact by inviting them to exchange correspondence and photos, mediating ongoing engagement and continuously reviewing the case plan with both parties.

Where both parties consent to contact, the social worker shall complete the following tasks:

a. engage with and prepare both parties for a face to face meeting (or for direct phone and email contact where this is the preference of the parties)
b. agree arrangements for a face to face meeting in a neutral venue (or arrangements for other forms of direct contact)
c. support the parties to meet or directly contact one another, including attending the meeting if that is the preference of either or both parties.

Where both parties are satisfied to proceed to contact without social work support, then they are welcome to do so. Support should remain available on request.

4.5.2.4. Post Contact and Case Closure

The social worker will support both parties post reunion by:

a. mediating a further meeting where requested by both parties
b. supporting both parties to exchange contact details by consent
c. reviewing the case and making contact with both parties regarding case closure, providing post-contact counselling/support where requested.

For the purposes of providing a tracing service, each application will be treated as a separate case and, generally speaking, it will not be possible to keep a case open in respect of a new specified person added after the initial application is received.

4.6. Specialist Tracing Service

The Birth Information and Tracing Act also empowers the Minister to direct the Agency and the Authority to undertake specialist tracing, where he or she is satisfied that this is necessary and in the public interest. This specialist tracing may involve the Agency or the Authority:

(a) undertaking a review of files to investigate whether there is evidence that a person has been the subject of an *illegal birth registration*;

(b) conducting a trace to locate a person or obtain information, for the purpose of (i) obtaining evidence or confirming that a person has been the subject of an *illegal birth registration*, or (ii) informing a person that he or she has been the subject of an *illegal birth registration*.

A direction from the Minister to undertake specialist tracing services must be in writing.

4.7. Application for Tracing by a Person Adopted under an Intercountry Adoption from outside the State

4.7.1. Making an Application

A person over who was born in another jurisdiction and adopted under an intercountry adoption may apply to the Authority where they wish to trace a person in that other jurisdiction.

4.7.2. Processing an Application

After the application has been received and registered by the Authority, the following steps should be followed:

4.7.2.1. Referral to the Central Authority in the Country of Origin

Where legally permissible (e.g. where the country of origin is not under international sanctions), the Authority shall forward the application to the central authority in the country of origin, asking that they convey any response to a request for contact or information directly to the applicant.

4.7.2.2. Support and Assistance

The AAI may provide an applicant with support and assistance in accordance with Section 63 of the Act. This may include assistance in relation to making an application for a tracing service or support in relation to reading and understanding records provided on foot of an application, and support where information could be potentially distressing to the applicant.

5. Registering a Contact Preference

5.1. Purpose of the Contact Preference Register (The Register)

The main purpose of the Contact Preference Register is to enable people to register their wishes in relation to contact with family, as well as provide contact details, information and items for sharing with specified family members. In contrast to the tracing service that supports people who are actively seeking contact, the Register is a way for people to signal all contact preferences, including a request for privacy. It also provides a mechanism to lodge information to be provided only in the event that the intended recipient chooses to come forward.

5.1.1. Who can express a preference on the Register?

The following persons are eligible to register a preference:

- An adopted person, a person who was subject to an *illegal birth registration*, a person who was nursed out, or boarded out, or a person who resided as a child in any institution listed in the schedule (relevant persons);
- The parent at birth of any person listed above;
- a person who is, or who believes themselves to be, a relative of a relevant person;
- The adoptive parent of an adopted child;
- The adoptive parent of an adopted child or adopted person, where the adopted child or adopted person is deceased;
- A person who provided care to a relevant person as part of a care arrangement.
  This includes the following:
    - A person who was in charge of a ward or area of an institution where the child resided and was cared for,
    - A person to whom a child was boarded out, or nursed out,
    - A person to whom an adopted child was fostered prior to their adoption.

All applicants to the Register must be over 18 years old.

5.1.2. What preferences can be registered, and what do they mean?

It is possible to register for varying levels of contact under two types of preferences:

1. A preference for contact
    a. Is seeking contact with a specified person;
    b. Is willing to be contacted by a specified person (this could include being willing to provide information if requested by a specified person);
    c. Is seeking information relating to a specified person;

2. A preference for no contact
    a. Is not willing to have contact of any kind;
    b. Is not willing to have contact with the specified person but is willing to provide information if requested by a specified person.

Where a preference for contact is registered

Where a preference for contact is registered by a parent, and subsequently an application is made for information by a relevant person, this preference is communicated by the Authority to the *recipient body*. The body, in turn, communicates it to a relevant person when releasing birth information (under section 2.6 of these guidelines).

Where a preference for contact is registered by any person eligible to join the Register (as in 4.1.1) and it relates to another person who has also registered a preference for contact, these two people will be considered a 'match' and will be processed under 4.4 of these guidelines.

Where a preference for no contact is registered

Where a preference for no contact is registered by a parent in the three month window following enactment, this is communicated as outlined under sections 2.4 and 2.5 of the guidelines. If a preference for no contact is registered by a relevant parent after the initial three month window, but before a relevant person applies for information, this will also be communicated as outlined under sections 2.4 and 2.5 of these guidelines.

More generally, where a preference for no contact is registered by any person eligible to join the Register, this preference for no contact will be communicated by the Authority where a match is made.

5.2. Making an application

An application to join the Register must be made in writing using the form specified by the Authority, accompanied by photographic identification (ID). A sample of the type of application form is set out at appendix 2, while the acceptable forms of ID are set out at appendix 3. This form may be completed digitally or in hard copy via post. An application may contain any of the categories of information set out in 5.2.1 of these guidelines.

An applicant's consent to the entry on the register must be sought in the application process. Applicants must also be presented with the following information:

- the purpose for which the information may be used and processed;
- the legal basis for which the information may be used and processed;
- the circumstances in which the information may be released to a third party;
- an applicant's right to amend or revoke their registered preference; and

5.2.1. What information can be captured in an application?

Information that may be captured on the form

The application form may seek to capture the following information, to the extent that the applicant is willing and able to provide it:

(i) Applicant Forename and surname, including names previously used;
(ii) Applicant Date of birth;
(iii) Applicant Address;
(iv) Category to which the applicant belongs (as set out in 5.1.1);
(v) The preference and level of contact the applicant wishes to register;
    - If seeking information, the type of information they are seeking;
    - Any information or provided items the person wishes to lodge on the Register for the purposes of sharing.
(vi) The following information in relation to a relevant person where this is known to the applicant:
    - the name of their parents, genetic relatives, or relevant guardian;
    - the place where care was provided as part of a care arrangement;
    - the adoption society or accredited body that made arrangements for their adoption.

The information at (vi) should be provided where known regardless of the category to which the applicant belongs. For example, the applicant may be a relevant person who knows that they were boarded out from a particular Institution to a family in a particular county. Alternatively, the applicant may be a mother who knows the Institution where her child was born, the adoption society through which they were adopted, and the name the child was given at birth.

5.3. Creation of an Entry on Register by the Authority

On receipt of an application to register a preference on the Contact Preference Register, the Authority shall:

(a) review the application form and check the accompanying ID;
(b) register the application on their system and create an entry in the Register on behalf of the applicant;
(c) acknowledge the application and provide case reference details to the applicant;
(d) check the Register for any existing entries that may be a match. If a match is identified, process the match in line with 5.5 of these guidelines.

5.4. Lodging of Information and Items by the Authority

On receipt of an application to lodge information or items to the Contact Preference Register, the Authority shall:

(a) review the application form and check the accompanying ID;
(b) register the information or items by:
    (i) creating an entry to the Register if no entry exists, and record the lodgement in the entry; or
    (ii) updating an entry to the Register if an entry exists to record the lodgement in the entry;
(c) create a reference number that links the lodgement to the entry on the Register;
(d) safeguard the information or item lodged.

5.5. Matching from the Register

Where a preference for contact has been made on the contact preference register, and subsequently, the Authority identifies a match in regard to this contact preference, the Authority shall:

- Confirm the details and preferences of the matched individuals
- inform the person that a match has been made;
- provide them with the contact details of the person with whom the match has been made;
- offer to facilitate and support contact; and
- facilitate and support contact, if requested.

Where a match is identified and it is for requesting information, the Authority will:

- inform the person that information has been requested from them, and what information is requested;
- offer to facilitate the sharing of that information; and
- facilitate the sharing of that information, if requested.

Where a match is identified and it is for the provision of information or items, the Authority will:

- inform the person that information or items have been lodged for them;
- if they wish to receive it, provide with them the information or item.

5.6. Updating or deleting entries on the Register

An applicant to the Register can apply to update or delete their entry to the Register at any time. The only section of an entry that cannot be deleted on request, is a record of an information session having taken place in relation to that applicant.

It is also possible for people who have lodged information or provided items to request the return of the information or items. This will be facilitated, so long as the information or item in question has not already been provided to the person with whom it was to be shared.

Any requests to update or delete entries to the Register, or return any items must be made to the Authority in the manner specified by the Authority.

5.7. Existing entries on the National Adoption Contact Preference Register

All entries under the National Adoption Contact Preference Register will remain valid, including contact preferences that have been registered by a parent. On enactment of the legislation, the Authority shall:

- create an entry in the Contact Preference Register for any entry that exists on the national adoption Contact Preference Register;
- transfer all information contained within that entry to the Contact Preference Register;
- delete or destroy the existing national adoption Contact Preference Register 6 months after enactment.

6. Safeguarding of Records

6.1. Introduction

6.1.1. Purpose

The purpose of this part is ensure the safeguarding of important historic and relevant records in relation to adoption, boarded out or nursed out arrangements, *illegal birth registration*s, and Mother and Baby and County Home Institutions.

6.1.2. Legislative Basis

Part 7 of the Birth Information and Tracing Act provides for the safeguarding of records. It provides for immediate safeguarding on commencement, and also enables the transfer of records to the Adoption Authority of Ireland, under a direction of the Authority.

6.2. Who Must Safeguard a Record?

To achieve the safeguarding of records, the Act introduces the concept of an *information source*. An information source is a **person, body or organisation** who holds relevant records and is obliged to safeguard those records. Information sources are further defined and categorised into primary information sources and secondary information sources, and are listed in the legislation. In addition to this, the legislation enables the Minister to prescribe a secondary information source where he reasonably believes a person is in procession of a relevant record.

Additionally, the legislation places an obligation on any person, body, or organisation regardless of whether or not they are designated an information source, who is in possession of a *relevant record* to inform the Adoption Authority of the existence of those records, and to safeguard them until transfer to the Authority can take place.

6.2.1. Primary Information Sources

- Adoption Authority of Ireland;
- Tusla, the Child and Family Agency.

6.2.2. Secondary Information Sources

- The Minister for Children, Equality, Disability, Integration and Youth;
- The Minister for Education;
- The Minister for Foreign Affairs;
- The Minister for Health;
- The data controller of the Access to Institutional and Related Records (AIRR) Archive
- The Health Service Executive;
- A registered adoption society (registered under section 3 of the Adoption Act 1952);
- An accredited body (as under section 3 of the Adoption Act 2010);
- A person prescribed by the Minister under Section 43(2).

6.3. What Records Must Be Safeguarded

Any record which falls under the definition of "relevant record" must be safeguarded. The definition of "relevant record" is **only** applicable to this chapter on safeguarding. It **does not** apply to information requests. Information requests cover **all** records held by a *recipient body* in relation to a relevant person (See Chapters 2 and 3).

The definition of a "relevant record" is outlined in the table below.

Relevant Record means a record...

...that contains any of the following:

- Birth Information;
- Early Life Information;
- Care Information; and/or
- Medical Information

relating to a Relevant Person

A communication, or note of communication, from a parent or genetic relative of a relevant person held by a primary or secondary information source

A photograph or other image of a relevant person's mother, father, or genetic relative

A communication, or note of communication, from a relevant person to a parent or genetic relative held by a primary or secondary information source

Or a record that is held...

... by the Department of Foreign Affairs relating to the departure from the State, in the period commencing on 1 January 1940 and ending on 31 December 1979, of a child -

- for the purpose of the effecting of their adoption outside the State; or
- Adopted under an adoption order by a person resident in a place outside the State, for the purpose of the child residing with the person

Or a record that is prescribed by the Minister

The Minister may prescribe a record as a relevant record where:

- The record relates to the care of a child or children;
- The record or part of it would be at risk of being destroyed or otherwise lost if it were not prescribed;
- The record has historical or social value and it is in the public interest that it be prescribed.

6.4. How Must Records Be Safeguarded

6.4.1. Primary Information Sources

The legislation requires that Primary Information Sources retain all relevant records in their possession. The Authority and the Agency shall not destroy any relevant records that they hold.

The legislation also obliges information sources to maintain all relevant records. This includes a prohibition on concealing, mutilating, or falsifying information on relevant records.

Under the legislation, it is an offence to conceal, destroy, mutilate, or falsify relevant records. This offence carries a penalty of up to 3 years in prison and/or a fine of up to €50,000. Offences shall be reported to An Garda Síochána for investigation.

6.4.2. Secondary Information Sources

The legislation requires that Secondary Information Sources retain all relevant records in their possession. Information sources shall not destroy any relevant records that they hold.

The legislation also obliges information sources to maintain all relevant records. This includes a prohibition on concealing, mutilating, or falsifying information on relevant records.

The obligation to retain and maintain records does not apply to records held by secondary information sources for which it there are obligations under the National Archives Act 1986.

Under the legislation it is an offence to conceal, destroy, mutilate, or falsify relevant records. This offence carries a penalty of up to 3 years in prison and/or a fine of up to €50,000. Offences shall be reported to An Garda Síochána for investigation.

In addition, the Authority may direct a secondary information source to provide a statement of the relevant records in their possession. If the Authority makes a direction, this also obliges the secondary information source to inform the Authority if they subsequently come into possession of a relevant record or become aware that a relevant record was in their possession that was not included in the original statement.

A statement must inform the Authority of the nature, current location, and condition of the relevant records. Personal data may only be included in such a statement to the extent that it is necessary to do so.

6.4.3 Transferring records to the National Archives

The National Archives Act 1986 requires that Departments or bodies specified in the schedule to the 1986 Act transfer records over 30 years old which are worthy of permanent preservation to the National Archives. Section 71 of the Birth Information and Tracing Act 2022 adds the Adoption Authority of Ireland to this schedule. The Child and Family Agency are not subject to the 1986 Act.

However, section 8(2) of the National Archives Act provides for retention of records in regular use in a body subject to the Act:

> *"An officer of a Department of State authorised for the purpose of this subsection may certify that for stated reasons a particular Departmental record, or a particular class or classes of Departmental records prescribed in accordance with subsection (11), which are more than 30 years old and are specified in the certificate are in regular use in that Department or are required in connection with its administration and that their transfer to the National Archives would seriously interfere with the administration of that Department."*

While members of the public still have a right to view records retained under section 8(2), subject to the exceptions contained in Section 8(4).

Consequently, the certifying officer in the *relevant body* should:

- prepare a schedule of the records being retained, and a certificate under the National Archives Act 1986, Regulations 1988, stating that they are in regular use by the body, and that to transfer them to the National Archives would interfere with their administration.
- Prepare a certificate under the National Archives Act 1986, Regulations 1988, stating that to make the record available to public inspection would or might cause danger or distress to a living person. This is then sent to the consenting officer in the Department of the Taoiseach for approval.

More details on this process is provided by the National Archives: https://www.nationalarchives.ie/services-to-government-and-courts/retaining-departmental-records/

Section 43 of the Birth Information and Tracing Act 2022 allows the Minister to designate a body as a secondary information source. Depending on the body in question, some will have requirements under the National Archives Act 1986 (for example Government Departments), while others will not (for example a religious organisation). As noted in section 6.4.2 (above), the obligation on a secondary information source to retain and maintain relevant records does not apply to records which are transferred to the National Archives in compliance with the National Archives Act 1986. A person is entitled to make a Subject Access Request to the National Archives under *GDPR*.

6.4.4 Transferring records from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth (DCEDIY)

Action 8.1 in the *Action Plan for Survivors and Former Residents of Mother and Baby and County Home Institutions* is that Government will "require that relevant Government Departments and State bodies prioritise ensuring that relevant original files are made publicly available in the National Archives of Ireland (NAI) in accordance with the terms of the National Archives Act 1986."

Part of this includes the transfer of several thousand files from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth (DCEDIY). This process is ongoing and is expected to be completed by the end of 2023. They will then be reviewed by the DCEDIY archivist with a view to subsequent transfer to the National Archives.

6.4.5. Guidance of preservation of records

Safeguarding in the archival sense can include preservation measures that help to protect the security and the integrity of the records. This will help reduce risk from potential deterioration of paper records due to inadequate environmental and storage conditions, but may also include restricted access to particular staff members within an organisation.

Basic preservation measures that will help reduce loss or damage to paper records include:

- storage of records in cool, dry and secure conditions;
- the use of archival standard acid free boxes and folders;
- the creation of finding aids, or catalogues, that reduce the need for over-handling of records;

- digitisation of records to create an access copy of original paper records;
- identification of at-risk records, including remedial and conservation intervention to avoid further loss; and
- development of a disaster plan, including steps to be taken in the event of an unforeseen circumstance such as flooding or fire.
- Paper records should not be stored in damp conditions or areas where temperatures within a storage area are likely to fluctuate.

Safeguarding of digital records, including born digital or electronic records and digitised surrogates of paper records, may also include restrictions on access and editing permissions, and should include the development of a digital preservation strategy, including possible migration of records over time to ensure continued access. Any ICT strategy should include as part of its core focus the long-term requirements around access, preservation and permanent archiving of digital records that have been deemed worthy or permanent preservation.

6.5. Obligations on persons who are not designated information sources

If a person other than an information source is in possession of a relevant record, they must inform the Authority of that fact as soon as is practicable. They are also obliged to retain and maintain the relevant record until the Authority can take possession of it.

6.6. Process for AAI to take ownership of records

Where a record is in the possession of a secondary information source, or another individual, the legislation empowers the Adoption Authority to transfer records into their care.

This process can take place in two different ways:

- At the request of the Secondary Information Source under Section 47 of the legislation;
- At the direction of the Adoption Authority under Section 48 of the legislation.

6.6.1. Transfer on Request of Adoption Authority

Where a transfer of records is on the request of the Adoption Authority the process is as follows:

- The Adoption Authority directs the Secondary Information Source to provide a statement, relating to the relevant records in its possession. The statement must be provided within three months of requesting.
    - If a record is incorrectly omitted from the statement, or comes into the possession of a Secondary Information source after the statement has been provided, the Information source must provide another statement within six weeks of its discovery.
    - The statement must specify all records held, their nature, current location, and the condition of the records.
    - The statement must not include any personal data unless it is necessary and proportionate to fulfilling its functions under this part.

- Once the statement is received by the Adoption Authority, the Authority may issue a direction for the transfer of the records, or a copy of the records, into their care. This may only happen where the transfer of the records is in the public interest.

- The decision to make a direction must consider:
    - Whether the record (or a copy) is at risk, and if so it must be transferred as a priority;
    - Whether the transfer of the records has been on the request of an information source;
    - The public interest.

- The direction must in writing, and specify the following:
    - The date on or before which the records must be transferred; this date must be within six months of the date of direction.
    - The format in which the record is to be transferred;
    - The reason for which the record is being transferred (public interest);
    - The intended use of the record;
    - The safeguards in place to store and maintain the record.

- The Authority is responsible for making the arrangements for the transfer of any records. These arrangement may include matters of copyright, licencing/re-use, costs for transfer or carriage, and other practical arrangements as pertain to the transfer of records.

6.6.2. Transfer on Request of a Secondary Information Source or other person.

A secondary information source, or a person in possession of a relevant record who is not a secondary information source (see 6.2 above), may request to transfer a relevant record to the Authority.

The request must in writing, and must specify the record to which the request relates, and be accompanied by a statement of the reasons for the making of the request. In the meantime, the person making the request is obliged to retain and maintain the record until the Authority arranges the transfer of the record(s).

6.7. AAI Powers of Search and Seizure

Under this legislation the Authority are empowered to enter, and inspect a place where it has reasonable grounds to believe there are relevant records held, for the purposes of safeguarding those records under this legislation.

A place can mean a dwelling, a building, or a vehicle. They may also inspect and take copies or extracts from records found in a search. Inspections are undertaken by Authorised Officers appointed by the Authority under Section 51 of the legislation.

7. Data protection

7.1. Introduction

The Birth Information and Tracing Act 2022 facilitates the processing of personal data, including special categories of personal data, in accordance with the General Data Protection Regulation (*GDPR*) and the Data Protection Act 2018. To support the timely release of information, it also enables the restriction of the following rights and obligations provided for under *GDPR* for the purposes of facilitating the processing of data as part of an application for information or tracing as per Section 68 of the 2022 Act:

(a) Article 14, obligation that a data controller should provide information to the data subject where personal data have not been obtained from the data subject;
(b) Article 18, the right to restriction of processing;
(c) Article 21, the right to object.

Article 12 will have an ancillary restriction due to the restrictions of these articles.

These restrictions are discussed in more detail in section 7.3 of this chapter.

As per section 67 of the Act, the Minister may outline suitable and specific measures, including measures specified in section 36(1) of the Data Protection Act 2018, to be taken to safeguard the fundamental rights and freedoms of data subjects in the processing of personal data, including special categories of personal data, under this Act.

This chapter sets out the necessary principles which must adhered to in order to ensure the effective and secure processing of all data.

7.2. General Principles

Where it is necessary and proportionate for the performance of his, her or its functions under the Birth Information and Tracing Act 2022, persons listed below may process personal data, including special categories of personal data, in accordance with the General Data Protection Regulation and the Data Protection Act 2018.

This applies to the following persons:

(a) the Authority;

(b) the Agency;

(c) the GRO;

(d) a *relevant body*;

(e) a secondary information source.

For the purposes of the Birth Information and Tracing Act 2022 both the Authority and the Agency are designated as data controllers in relation to personal data processed by them for the purposes of the performance of their functions under the Birth Information and Tracing Act 2022 respectively.

As with all data processing arrangements, there are seven key principles related to the processing of personal data, established under Article 5 of the *GDPR*, which controllers must comply with when collecting and otherwise processing personal data. They are as follows:

1. Lawfulness, fairness, and transparency;
2. Purpose limitation;
3. Data minimisation;
4. Accuracy;
5. Storage limitation;
6. Integrity and confidentiality;
7. Accountability.

Further information and guidance can be sought by consulting each *relevant body*'s Data Protection Officer, the 2018 Data Protection Act, and the Office of the Data Protection Commissioner. Each *relevant body* should apply its own existing *GDPR* policy for the purposes of handling data, subject to the lawful basis for processing set out in the Birth Information and Tracing Act and the restrictions provided for under Section 68 of the 2022 Act, and taking account of the procedures set out in these guidelines.

7.3. Restriction of rights and obligations under General Data Protection Regulation

In order to ensure the efficient operation of the processes outlined in the Birth Information and Tracing Act 2022, certain rights and obligations provided for in the *GDPR* are restricted.

As defined in Section 68 of the 2022 Act, the rights and obligations provided for in the following Articles of the General Data Protection Regulation, in so far as those rights and obligations relate to the processing of personal data and special categories of personal data by a person under the Act, are restricted to the extent necessary and proportionate to enable the person to perform his or her functions under this Act:

(d) Article 14, obligation that a data controller should provide information to the data subject where personal data have not been obtained from the data subject;
(e) Article 18, the right to restriction of processing;
(f) Article 21, the right to object.

Article 12 will have an ancillary restriction due to the restrictions of these articles.

The justification for these restrictions is noted below:

1) Article 14, obligation that a data controller should provide information to the data subject where personal data have not been obtained from the data subject;

It would be near impossible for a data controller to comply with this obligation given the historic nature of the records, the volume and diversity of the records and the different social norms and administrative practices in place at the time they were created. Some records will have been collected by the data controller, for instance the adoption file retained by the Adoption Authority. In other cases, such as mother and baby home records, the Child and Family Agency is now the data controller, however, the records were created by the relevant religious orders or governing authorities.

2) Article 18, the right to restriction of processing;

A parent named in the records may wish to restrict processing on grounds that they believe there are inaccuracies. The onus would then lie with the data controller to verify the accuracy or otherwise of the disputed historical record and ensure that any processing of the data is restricted while this verification is taking place. The verification may be wholly impossible or may be extremely difficult and onerous in terms of historic records. During the time that the data controller is carrying out the verifications, the data cannot be processed and this will have implications for an application made by an adopted person. In cases where accuracy cannot be verified or remains contested, it could result a restriction of lengthy and indefinite duration, during which time the rights of the other party (i.e. the applicant) to their origins information cannot be vindicated. It may be noted that the right to rectification is not restricted and, so, a person with a concern in relation to inaccuracies on a historical record would be able to request rectification, for example, by providing a clarifying statement to be appended to the record.

3) Article 21, the right to object;

There are currently a minority of parents named on birth certificates who have refused to provide consent to the release of their names meaning that, in some cases, redacted birth certificates are released to applicants. The core purpose of the legislation is to change this process and to enshrine in law the right of a person to know his or her origins and provide for the release of a birth certificate and birth information to adopted people and others in all cases.

By restricting this Article 21 right, data controllers would no longer be obliged to consider applications of objection to processing on a case by case basis and this would reduce delays and blockages to the release of origins information to an adopted person.

These restrictions can be highlighted to individuals should they attempt to object to their data being processed as a part of the processes enabled by the Birth Information and Tracing Act 2022. As highlighted above, it should also be noted that other rights will remain open to data subjects, including the right to make a subject access request under Article 15 and the right to rectification under Article 16. The right to rectification is particularly relevant for mothers where they believe there is an inaccuracy on the file.

7.4. Data Sharing Arrangements

In order to ensure the effective processing of data under the processes noted in these guidelines, enabled by the Birth Information and Tracing Act 2022, a specific Data Sharing Agreement (DSA) will be agreed between the AAI and Tusla, known as the Parties to the agreement.

8. Monitoring and review of legislation

8.1. Introduction

8.1.1. Purpose

The purpose of this chapter is to outline the general principles for the monitoring and review of the operation of the Birth Information and Tracing Act. The legislation requires that a review of the operation of the Act will commence within 2 years of the enactment of the legislation.

8.1.2. Legislative Basis

Section 70 of the Act states:

*"**70.** (1) The Minister shall, not later than 2 years after the coming into operation of this section, commence a review of the operation of this Act, other than Parts 8 and 9.*

(2) In conducting a review under subsection (1), the Minister shall consult with such persons, including relevant persons, as he or she considers appropriate.

(3) The Minister shall cause a report in writing of the findings of the review under subsection (1) to be prepared and, as soon as may be after it is prepared, shall cause copies of the report to be laid before each House of the Oireachtas."

8.2. Scope of the Review

This review will cover the operation of all parts of the legislation, except for Part 8 (Amendment of the Succession Act) and Part 9 (Amendment of the Civil Registration Act).

As such, the following must be reviewed:

- Definitions under Part 1
- Applications for information under Parts 2, 3, and 4.
- Operation of the Tracing Service under Part 4
- Operation of the Contact Preference Register under Part 6
- Safeguarding of Relevant Records under Part 7

8.3. Review of Definitions under Part 1

As part of the review process, DCEDIY will conduct a review of the Act's definitions. In particular, this review will focus on definitions which define:

- Who is affected by the Act (e.g. Adopted Person, Relevant Person etc.)
- What information must be released under the Act (e.g. Care Information, Early Life Information)

The goal of the review will be to ensure that the definitions encompass the full range of persons with questions in relation to their origins who need to be encompassed by the term "relevant person", and that information release is as complete and wide ranging as possible.

In considering these definitions, DCEDIY should consult with stakeholders and affected persons.

8.4. Review of Information and Tracing Services

DCEDIY will collect, collate and analyse aggregated data from all recipient bodies on the operation of information and tracing services under Parts 2, 3, 4 and 5 of the Act. This review will cover all

elements of the Information and Tracing services, including data on counselling and support services.

All data collected for this purpose will be anonymised, aggregated and will be analysed at group level. The Authority, the Child and Family Agency, and DCEDIY will agree on the quantitative data to be collected and will share that data with DCEDIY at regular intervals throughout the first two year period in order to monitor the emerging picture of the operation of the information and tracing services.

DCEDIY meets with Tusla Adoption Services and the Adoption Authority of Ireland on a regular basis as part of its ongoing governance arrangements with both bodies. Any issues arising can be raised at these meetings for attention.

DCEDIY will also consult with relevant persons and other stakeholders and affected parties.

The goal of this review will be to create a picture of the operation of the information and tracing services to inform any necessary amendments to the legislation, changes to the guidelines, and operational improvements to ensure the delivery of a robust and timely service in line with the principles underpinning the legislation. The review will focus, in particular, on ensuring that there is no group of relevant persons that is experiencing difficulty in accessing their information, and whether there are particular types of information that are not being easily accessed by relevant persons.

In particular, the review will be informed by the same core principles as the rest of these guidelines:

Principles

1. **Presumption of Validity:** A recipient body should consider that persons applying for access to their identity information have a legitimate belief that there is identity information held by the recipient body.

2. **Supportive approach:** Where requested, the person applying will be supported in their application, the receipt of their identity information and in relation to any further services for which they may be eligible and which may usefully be signposted.

3. **Active communications:** The recipient body will aim to progress each application in a timely manner, and where a delay is experienced or expected, the recipient body will actively engage with the person to keep them informed.

4. **Release of information:** In line with the spirit of the legislation, every effort should be made to provide access to the requested identity information, as well as to other information, the disclosure of which is not prohibited by law, and which could benefit the person in understanding their birth origin story.

Appendices

Appendix 1 List of institutions

This list is taken from the schedule to the Birth Information and Tracing Act 2022.

- Mother and Baby Home Institutions
- St. Patrick's / Pelletstown, Navan Road, Dublin
- The Tuam Children's Home, Tuam, Co. Galway
- Bessborough Mother and Baby Home, Cork
- Manor House, Castlepollard, Westmeath
- Sean Ross Abbey, Tipperary
- Árd Mhuire, Dunboyne, Meath
- Bethany Home, Dublin
- Denny House, Dublin
- Miss Carr's Flatlets, Dublin
- The Regina Coeli Hostel, Dublin
- The Castle Newtowncunningham, Co. Donegal
- The County Clare Nursery, Kilrush, Co. Clare
- Belmont Flatlets, Dublin
- St. Gerard's, Dublin
- B. County Home Institutions
- Sacred Heart Home and Hospital, Carlow
- St. Felim's County Home and Hospital, Cavan
- St. Joseph's Hospital, Ennis
- Cork County Home and District St Finbarr's
- Our Lady of Lourdes Home, Midleton, Cork
- Mount Carmel Home, Clonakilty, Cork
- St. Patrick's Hospital, Fermoy, Cork
- St. Joseph's Home, Stranorlar, Donegal
- Dublin Union (St Kevin's Institution)
- St. Brendan's Home, Loughrea, Galway
- St. Columbanus Home, Killarney, Kerry
- St. Vincent's Hospital, Athy, Kildare
- St. Columba's County Home, Thomastown, Kilkenny
- St. Vincent's Hospital, Mountmellick, Laois
- St. Patrick's Home, Carrick-on-Shannon, Leitrim
- St. Ita's Home, Newcastlewest, Limerick
- St. Camillus Hospital, Limerick
- St. Joseph's Hospital, Longford
- Sacred Heart Home, Castlebar, Mayo
- St. Joseph's Home, Trim, Meath
- St. Mary's Hospital, Castleblayney, Monaghan
- St. Vincent's Hospital, Tullamore, Offaly
- Sacred Heart Home, Roscommon
- St. John's Hospital, Sligo

- Hospital of the Assumption, Thurles, Tipperary
- St. Patrick's Hospital, Cashel, Tipperary
- St. John's Hospital, Dungarvan, Waterford
- St. Mary's Hospital, Mullingar, Westmeath
- St. John's Hospital, Enniscorthy, Wexford
- St. Colman's, Rathdrum, Wicklow

Appendix 2 Example Application Form For Recipient Bodies.

The application form below is an indicative example for relevant bodies to draft their application forms.

The Birth Information & Tracing Act 2022

Birth Information and Tracing Application Form for a Relevant Person

Please Note: A relevant person who was adopted from another country (intercountry) must make an application directly to the Adoption Authority of Ireland

Please use this form to apply for an Information Service if you are one of the following:

- **A relevant person** (see information box below)
- **A son/daughter of a relevant person** (a son or daughter of a relevant person who is deceased is known as a qualifying person)

**Please see appendix 2 for more details.*

- **A next of kin** (A next of kin of a relevant person where the relevant person died as a child while resident in a mother and baby home or institution, also known as a qualifying relative)

**Please see appendix 2 for more details.*

The four categories of "relevant person" for the purpose of obtaining information are:

e) an adopted person (16 years or over)
f) a person who is, or suspects they are, the subject of an illegal birth registration,

g) a person who was nursed out or boarded out or suspects they may have been nursed out or boarded out
h) a person who does not fall into any of the above categories but who resided as a child in an institution listed in the Act.

Sections of the form:

Please read this important note before completing your application:

Please use BLOCK CAPITALS when filling in this form

*By completing this application form you, or the person authorised by you, will help us to register your application for an information or tracing service, or both, depending on the option(s) you choose.

We understand that because of the personal and sensitive nature of the information you are providing, you may have questions about the form. If you do, please feel free to contact us at Tel: 0818 44 55 00 where we will be happy to assist you.

This application can be returned to the following address: PO box 13018 Dublin 15 Ireland

Section 1: Applicant details

(If you are acting on behalf of the Applicant, please provide the applicants details below, and provide your own details in Section 1- Part B)

Please tick the appropriate box(es) (you can tick more than one box)

Relevant persons:

Category:	Tick below:
A. I was adopted in Ireland, and I am 16 years of age, or over Name of Adoption Agency (if known): _____	☐
B. I was born in Ireland and placed for adoption in another country Name of other country (if known): _____	☐
C. My birth was incorrectly/illegally registered Any details of place of birth (if known): _____	☐
D. I was nursed or boarded out or in a mother and baby home or county home/ institution Name of home/institution (if known): _____	☐

I am a son/daughter of a relevant person: *please note a son/daughter may only apply for information.

Category:	Tick below:
I am a son/daughter of a relevant person (listed above) who is now deceased	☐
From the above categories, which best describes the deceased relevant person? Category A Category B Category C Category D	☐ ☐ ☐ ☐

I am a next of kin:

Category:	Tick below:
I am a next of kin of a relevant person (where the relevant person died as a child while resident in a mother and baby home or institution) Name of the mother and baby home/institution the child was resident in? _____ Relationship to the child _____	☐

Section 1

Applicant Details continued

First Name:	**Surname:**
Any other names you may be known by or may have used in the past:	
Date of Birth	**(e.g., 01/01/1964)**
Address: (please include Eircode, if known) _____ _____ _____	
Phone: **Landline:**	**Mobile:**
Email Address:	

***This section should only be filled out by a son/daughter of a relevant person or next of kin of a child who died in an institution.** Please note we will use this information to assist us in locating the relevant records. (*If you know that the relevant person previously sought information or requested a trace, please state this in Section 2, Previous Enquiries).*

Relevant person/child's Information

First Name:	**Surname:**
Any other names they may be known by/have used in the past (where applicable):	
Date of Birth (if known)	**Approximate age while in the home/agency or boarded out/ on historical records (if known)**

_____	_____

Any details about the place of birth/ name of the home or agency or institution where the person may have spent time (if you do not have information, please leave this space blank):

_____

_____

_____

_____

_____

_____

***This section should be filled out by an adopted person only**. Please note we will use this information only to assist us in locating your record and we will not contact your adoptive parents

Adoptive Parents' Information

Mothers name:	Fathers name:

Address of adopted parents at the time of the adoption:

_____

_____

_____

Section 2: Previous Enquiries

Have you previously looked for information, traced, or had contact with a relative (either on your own or through an adoption agency)?

Yes ☐ No ☐

If you answered 'Yes' please give details

_____

_____

_____

_____

_____

_____

_____

_____

How would you like us to communicate with you?

Email ☐ Post ☐ Telephone ☐ Text ☐

*Please note we can only send acknowledgements by email or post. Please confirm if you wish to receive an acknowledgement Yes ☐ No ☐

Section 2 – Part B

If you are an authorised person acting on behalf of the applicant, please give your details below

First Name:	**Surname:**
Date of Birth	**(e.g., 01/01/1964)**
Address: (please include Eircode if known) _____ _____ _____	
Phone: **Landline:**	**Mobile:**
Email Address:	

Note: **By completing Section 1 – Part B you are confirming that the applicant has authorised you to act on their behalf. Please note that we will reply directly to the relevant person, rather than to the person mentioned in section 1- Part B.**

Section 3: Information Service

If you are seeking information from a file/record, please complete this section.

Please tick the box(es) of the information you are applying for (you can tick as many boxes as you wish): (Please see appendix 1 for guidance)

Category of Information:	**Tick below:**
If you wish to apply for all the information which follows please tick the box directly across.:	☐
Birth Certificate (THIS APPLIES ONLY TO A RELEVANT PERSON)	☐
Birth information only	☐
Early life information only	☐
Care information only	☐
Medical information only	☐
Provided items only	☐
Medical Information relating to genetic relatives only* (If you wish to receive this information you can access it from your nominated doctor. Please fill in your doctor's details below)	☐

Genetic Medical Information Requests

(It is important to know if you are seeking this information you will need to supply your doctor's details).

Doctor's Details	
Name:	
Address:	
Email address:	
Phone Number:	

Section 4: The Contact Preference Register (CPR)

The Contact Preference Register (CPR) was created in 2022 and has replaced the National Adoption Contact Preference Register (NACPR).

The main purpose of the Contact Preference Register is to enable information sharing and contact between family members who have been separated either through adoption, being boarded out/at nurse, or those who resided in an institution or had their births illegally registered. The Register also provides you with an opportunity to lodge a contact preference, including a request for privacy. As an applicant to the register, you can lodge an item (letter, photograph etc.) for a specified person, which will be given to that person if they too join or have previously joined the register.

If you previously joined the NACPR your details will automatically transfer to the CPR. This includes the contact preferences you chose on your application form for the NACPR. If you would like to update your preferences or any other details, such as your address or telephone number, please complete an application to the CPR and return it to the Adoption Authority. Once received, the Authority will update your details on the CPR.

If you did not join the old National Adoption Contact Preference Register, we would recommend that you apply for the new register.

If you would like to join or update your details on the CPR, please click **here**, or visit the Birth Information and Tracing website where you can find more information and complete or download the new Contact Preference Register application form.

Website: birthinfo.ie

You can also request a CPR application form by emailing the Adoption Authority at: records@aai.gov.ie or by post: **AAI, PO Box 9957, Dublin 4.**

Section 5: Applicant's signature and identification
Photo identification and proof of address:

We need a photo identification and proof of address to process this application to ensure we can keep your data safe and always protected. We can only process applications when we have verified your identity. Please provide one form of photo ID and one form of proof of address (This documentation DOES NOT need to be certified).

Accepted photo ID includes:

(Please tick one of these boxes)

Category:	Tick Below:
Passport	☐
Driver's Licence	☐
Garda Age Card	☐
Other	☐

Proof of Address:

(Please tick one of these boxes)

Category:	Tick Below:
Utility bill	☐
Bank statement	☐
Revenue letter	☐

Signature:
Please print your name _____

Please sign your name _____

We may need additional information to process your application and we will contact you if needed.

Data Protection/GDPR Notification

By completing this application form, you (the applicant) have provided [Relevant Body] with your personal data (personal information) or the personal data of someone that you have authorised to act on your behalf, to provide access to information in accordance with the Birth Information and Tracing Act, 2022.

Your privacy is important to us, and it is important to us that you understand exactly why we need to collect information about you (your personal data) and what we will use it for. We have provided you with the Information and Tracing Data Protection Notice which details this information.

Appendix 1: Information released under the Birth Information and Tracing Act 2022

Birth certificate	**means a document issued under section 13(4) of the Civil Registration Act 2004 (short and long version if available).**
Birth information	means, in relation to a person, the following information relating to the person at the time of his or her birth: (a) the date, place and time of his or her birth; (b) his or her sex; (c) his or her forename and surname; (d) the forename, surname, birth surname, address, occupation, date of birth, civil status and, where applicable, former surname of his or her mother; (e) the birth surname of his or her mother's mother; (f) the forename, surname, birth surname, address, occupation, date of birth, civil status and, where applicable, former surname of his or her father; (g) the birth surname of his or her father's mother;
Care information	subject to *subsection (2)*, means, in relation to a person who, at any time in the period following his or her birth and ending on the date on which he or she attained the age of 18 years, was the subject of a care arrangement, information in relation to the care arrangement, and includes— (a) the name of any person who was a party to the care arrangement, (b) where the person was cared for as a resident of an institution specified in the *Schedule*— appendix 1 (i) the name of the person in charge of the institution, and (ii) where the person was cared for in a part of the institution, the name of the person in charge of that part, at the time the care was provided, (c) the place at which the care was provided, (d) the dates on which the care arrangement commenced and ceased, and (e) the name of the person who made the care arrangement;
Medical information	means, in relation to a person, information relating to his or her medical history
Genetic relative information	means, in relation to a person the following information: (a) whether the person has a genetic relative, or had such a relative who is deceased; (b) where the person has a genetic sibling or had such a sibling who is deceased— (i) the sex of the genetic sibling, and (ii) whether the genetic sibling is or was older or younger than the person;
Medical information relating to a genetic relative	Medical information relating to a genetic relative includes the medical history of their relevant parent or genetic relative. This information is only provided in cases where the information involves a genetic or heredity medical condition that is relevant for the maintenance of the relevant person's health.

"incorrect[2]" birth registration information (also known as unlawful/illegal/ Illegal adoption)	means, in relation to a person who is or has been the subject of an incorrect birth registration— (a) the circumstances under which the person became the subject of an incorrect birth registration, and (b) the name of the person who made arrangements for the incorrect birth registration
Early-Life Information	subject to *subsection (2)*, means, in relation to a person, information that relates to him or her at any time in the period following his or her birth and ending on the date on which he or she attained the age of 18 years and includes— (a) the place at which he or she resided and the dates during which he or she resided at that place, (b) where applicable, information relating to his or her baptism or any other ceremony of a religious or spiritual nature performed in the period in respect of him or her, which shall include, where available— (i) information on the date and place of the baptism or ceremony, (ii) in the case of his or her baptism— (I) the certificate of baptism, and (II) the entry in a register of baptisms, and (iii) in the case of any other ceremony of a religious or spiritual nature performed on him or her, any equivalent document to a document specified in *subparagraph (ii)*, (c) his or her birth weight, (d) information on his or her health, physical or emotional development, (e) information on any medical treatments, procedures or vaccinations administered to him or her, (f) the duration of the period during which his or her mother remained with him or her in the same place of residence, and the dates on which that period commenced and ended, (g) information on whether he or she left the place referred to in *paragraph (f)* with, or separately from, his or her mother, (h) information on whether any person, being a parent or other genetic relative of him or her, visited or inquired in relation to him or her, which information includes the degree of relationship of the other person to him or her, but does not include the name of the other person, (i) information on whether any person made arrangements for the adoption of the person, whether or not an adoption was effected in respect of him or her, which information includes the name of the person who made the arrangements, and (j) where an adoption was effected in respect of him or her, the name of each adoptive parent;

[2] Incorrect is the term used in the legislation however the term illegally registered is the more accepted term.

Provided item	means an item, including a letter, photograph, memento or other document or object held by a relevant body that was provided, whether to the Agency, Authority or any other person, by or on behalf of a parent or genetic relative of a relevant person, or another person involved in the provision of care of the relevant person, for the purpose of it being made available to the relevant person in the event that it were to be sought by or on behalf of him or her, whether the items have been so provided before, on or after the date on which— (a) this section comes into operation, or (b) the relevant person became a relevant person, and includes an item lodged in accordance with *section 39(1) subject to this section, a person may-(a) when making an application under section 38 (3), or (b) where there is an entry in the register in respect of him or her, lodge with the authority information or an item which the person wishes to be shared with such person as he or she may specify.* (NB. Section b above and reference to section 39(1) applies to the Adoption Authority only)

Appendix 2: Eligibility as the son or daughter or the next of kin of a relevant person

Son or daughter

The son or daughter of a relevant person is termed a "qualifying person" in the Act.

You can make an application for information if the relevant person (your parent) is deceased, and the relevant person's parents are also deceased (your grandparents).

Next of kin

The next of kin of a relevant person is termed "a qualifying relative" under the Act.

You may make an application for information if the relevant person died as a child in an institution.

For the purposes of an application, "next of kin" can mean one of the following:

- a deceased relevant person's mother or father.
- The relevant person's brother(s) or sister(s), if the deceased relevant person's parents are deceased the relevant person's uncle or aunt, if the relevant person's parents and siblings (if any) are deceased
- The relevant person's niece(s) or nephew(s), if the relevant person's parents, siblings (if any), and aunts and uncles (if any) are deceased,

Appendix 3 Acceptable forms of identification for applications for information and tracing

Applicants will need to provide their

- name, and
- date of birth,

A copy of current photographic ID which contains both the applicant's name and date of birth (such as a passport or driver's licence) will be sufficient in the vast majority of cases. It is not required that these copies should be authenticated by An Garda Síochana. Where certain ID is not available to the applicant, the relevant body may accept other forms of identification at their discretion.

If the applicant is a son / daughter of a relevant person, they should provide a birth certificate confirming their status and, where applicable and available, a death certificate in respect of the relevant person. In some instances an affidavit may be sought in the context of an extended family member. Other legal documentation may also be supplied.

Appendix 4 Counselling and Supports

Introduction and Overview

The Birth Information and Tracing Act 2022 makes a number of references to supports for relevant persons and parents. It is important to ensure that such support is offered in an appropriate and sensitive way.

A key principle of offering supports in this area is that there is a broad spectrum of supports available. This includes less intensive supports (for example, assisting a person to make an application under the legislation, or providing assistance in understanding some of the terminology used in original records), through to intensive counselling support. The level of support which might be required by appropriate for an individual will depend on their circumstances and experience. The below table sets out the supports available.

Type of support	Who is covered	Provider
Support in making an application. The Agency and the Authority can provide assistance to a person making an application for information, an application for a tracing service or an application to join the register.	Persons who were adopted, nursed out, boarded out, or subject to an illegal birth registration (relevant person) Son or Daughter of a relevant person who applies under Part 3 Next of Kin who applies under Part 4 Person eligible to apply for trace Person eligible to apply to the register	Agency Authority
Support in understanding records received. The Agency and the Authority can provide support for the interpretation and understanding of information and records provided on foot of the application. The Agency and the Authority can provide counselling and support to a person following provision of information of records.	Relevant person Son or Daughter of a relevant person who applies under Part 3 Next of Kin who applies under Part 4	Agency Authority
Counselling support for parents expressing a preference for no contact.	A parent	Agency

A parent registering a no contact preference will be offered counselling, if requested, the Authority will share their contact details with the agency who will arrange the provision of counselling.		
Counselling support for parents and relevant persons. A relevant person or a parent of a relevant person may request counselling support.	Parents Relevant person	Agency

Additional supports

Who is covered	Who provides	Nature of service
Adopted children **Adoptive parents** Barnardos provides a specialist therapeutic service to adopted children and teenagers who were born abroad or in Ireland and to their parents, including children adopted from foster care.	Barnardos	A national confidential and professionally staffed helpline and email advisory service. An email advisory service – adoption@barnardos.ie. Advisory sessions for adoptive parents. Parents may have questions about attachment, school issues, sharing background information and identity development among many other issues. Therapeutic sessions with adopted children and teenagers individually or together with their parents. Group work with children and teenagers. Group support and training for adoptive parents
Parents Barnardos provides a supportive service to parents who are referred by Tusla.	Barnardos (on referral from Tusla)	Group support for mothers. Individual therapeutic sessions for parents. A national confidential and professionally staffed helpline An email advisory service – adoption@barnardos.ie
Adults who were adopted as children Barnardos provides a supportive service to people who were adopted as children and who are referred by Tusla or via self referral.	Barnardos (on referral from Tusla)	Group support for adopted adults. Individual therapeutic sessions for adopted adults A national confidential and professionally staffed helpline

		An email advisory service – adoption@barnardos.ie
People who were Boarded out or Nursed out Barnardos provides a supportive service to people who were boarded out or nursed out.	Barnardos (on referral from Tusla)	Since 2022, Barnardos has provided a therapeutic service for people who were boarded out or nursed out as children.
People whose births were illegally/incorrectly registered Barnardos provides a supportive service to people whose births were illegally registered.	Barnardos (on referral from Tusla)	Individual therapeutic sessions for adults whose births were illegally registered and to their family members Individual therapeutic sessions for adopted adults and birth family members on referral from TUSLA • Group support to birth mothers and adopted adults • A national confidential and professionally staffed helpline • An email advisory service – adoption@barnardos.ie
People whose births were illegally/incorrectly registered	National Counselling Service	Counselling for individuals who were the subject of an illegal birth registration is available from the National Counselling Service.
Former residents of Mother and Baby Homes	National Counselling Service	Access to the National Counselling Service for former residents may be made by direct self-referral.
Individuals who suffered abuse or neglect as children	National Counselling Service	Access to the National Counselling Service for individuals who suffered abuse or neglect as children, either within a family or in an institution, may be made by direct self-referral.

Appendix 5 Template Text

This appendix provides sample text which relevant bodies can use in communications with persons seeking information.

Text for use when releasing personal information containing archaic/objectionable language:

Option 1- To be used in all cases unless Option 2 applies:

"You may be receiving important personal information that you have not previously seen or had access to.

You may also be receiving documents where archaic or objectionable terminology has been included. The Department/Relevant Body regrets any hurt and offence that such language may cause."

Option 2- To be used where the term 'illegitimate' has been included in the data being released:

"You may be receiving important personal information that you have not previously seen or had access to.

You may also be receiving documents where archaic or objectionable terminology has been included, for example, the term 'illegitimate' which was removed from Irish law by the Status of Children Act 1987. The Department/Relevant Body regrets any hurt and offence that such language may cause."

Cover note to be sent to nominated medical practitioner:

Dear Dr XX,

Under the Birth Information and Tracing Act 2022, adopted people, people who were boarded out, people who were the subject of an illegal birth registration and others are entitled to apply for their birth and early life information. This information is released directly to the applicant.

In some cases, people are also entitled to apply for the medical information of a genetic relative. Where this information exists, and where it may be relevant to the health of a relevant person, it will be released. Given the sensitive nature of third party medical information, this information is released through a nominated medical practitioner.

Please find enclosed a Medical Information Statement compiled by [relevant body] following an application for information by XX made under Part 2, Section 16 of the Birth Information and Tracing Act 2022. We have been advised during their application that you are their nominated medical practitioner.

Please note that this statement provides an account of any genetic medical conditions found during [relevant body's] search of their records. It should be noted that this statement is not intended as a substitute for the proper management of the applicant's health. The records that were used to inform this statement are third party in nature and cannot themselves prove or disprove the presence or absence of a genetic medical condition. In addition, the applicant may be receiving important personal information that they have not previously seen or had access to. Due consideration should be given to the applicants wellbeing following discussion of this statement and should they require additional supports, they can contact [relevant body] on 01XXXXXXX.

The records themselves may contain archaic or objectionable terminology which, for the purposes of full disclosure, has been included in the final Medical Information Statement. [Relevant body] regrets any hurt and offence that such language may cause.

Kind regards,

YY,[relevant body]

"No files found" sample letter:

Dear XX,

Please note that following your application for medical information relating to a genetic relative, [relevant body] can confirm that we have no records on file which contain information relating to genetic medical conditions. It should be noted that this relates only to files available to [relevant body]. The absence of records cannot itself prove or disprove the presence or absence of a genetic medical condition. Should you have any further concerns relating to your medical health, please contact your primary medical practitioner. For further support please contact our dedicated phone line on 01XXXXXXX.

Kind regards,

YY,[relevant body]

Appendix 6 – List of Hereditary Medical Conditions (See Chapter 3)

Description	OMIM number	Description	OMIM number
Loeys-Dietz syndrome Type 3	613795	Adult-onset vitelliform macular dystrophy	153700
3-Hydroxyisobutryl-CoA Hydrolase Deficiency (HIBCHD)	250620	Agammaglobulinaemia (x-linked)	300755
46XY Sex Reversal 6 (SRXY6)	613762	Agammaglobulinemia and isolated hormone deficiency	307200
Aarskog-Scott Syndrome	305400	Aicardi Goutieres syndrome Types 2, 3, 4, 5 and 6	610181, 610329, 610333, 612952, 615010
Abetalipoproteinemia (also known as aconthocytosis, microsomal triglyceride transfer protein deficiency and Bassen-Kornweig syndrome)	200100	Aicardi-Goutieres Syndrome 1 (AGS1)	225750
Achondrogenesis Type 1a	200600	Alagille Syndrome	118450
Achondrogenesis Type 1b	600972	Alexander Disease (ALX)	203450
Achondrogenesis Type 2	200610	Allan-Herndon-Dudley Syndrome	300523
Achondroplasia (ACH)	100800	Alpha Thalassaemia/mental retardation Syndrome* (ATRX)	301040
Achromatopsia 2 (ACHM2)	216900	Alpha Thalassemia	141800
Achromatopsia 3 (ACHM3)	262300	Alpha-1-antitrypsin deficiency	+107400 (where two Z alleles are inherited)
Achromatopsia 4 (ACHM4)	613856	Alpha-Mannosidosis	248500
Achromatopsia 5 (ACHM5)	613093	Alport Syndrome	301050
Achromatopsia 6 (ACHM6) (autosomal recessive only)	610024	Alport Syndrome	203780
Achromatopsia 7 (ACHM7)	616517	Alport Syndrome (Autosomal Dominant)	104200
Acute Intermittent Porphyria (AIP)	176000	Alzheimer's Disease - early onset	104300
Acute Recurrent Autosomal Recessive Rhabdomyolysis	268200	Alzheimer's Disease - early onset (Types 3 and 4)	607822, 606889
Adenylosuccinate lyase deficiency (ADSLD)	103050	Amyotrophic Lateral Sclerosis (ALS) 6	608030
Adrenal Insufficiency Congenital, with 46, XY sex reversal, partial or complete	613743	Amyotrophic Lateral Sclerosis 1 (ALS1)	105400
Adrenoleukodystrophy (Adrenomyeloneuropathy) (ALD)	300100	Amyotrophic lateral sclerosis 10, with or without frontotemporal dementia	612069
Adult Syndrome	103285	Amyotrophic lateral sclerosis 11	612577

Description	OMIM number	Description	OMIM number
Amyotrophic lateral sclerosis 14, with or without frontotemporal dementia	613954	Arrhythmogenic Right Ventricular Cardiomyopathy/ Dysplasia (ARVC/D), Autosomal Dominant	
Amyotrophic lateral sclerosis 15, with or without frontotemporal dementia	300857	Arterial Tortuosity Syndrome	208050
Amyotrophic lateral sclerosis 17	614696	Arthrogryposis Distal 2A (DA2A) Freeman-Sheldon syndrome	193700
Amyotrophic lateral sclerosis 18	614808	Arthrogryposis Distal type 1A (DA1A)	108120
Amyotrophic lateral sclerosis 19	615515	Arthrogryposis Distal type 3 (DA3) Gordon syndrome	114300
Amyotrophic lateral sclerosis 2, juvenile	205100	Arthrogryposis Distal type 5 (DA5)	108145
Amyotrophic lateral sclerosis 21	606070	Arthrogryposis Distal type 5D (DA5D)	615065
Amyotrophic lateral sclerosis 22 with or without frontotemporal dementia	616208	Arthrogryposis Distal type 7 (DA7)	158300
Amyotrophic lateral sclerosis 23	617839	Arthrogryposis Distal type 8 (DA8)	178110
Amyotrophic lateral sclerosis 4, juvenile	602433	Arthrogryposis multiplex congenita, distal, type 2B	601680
Amyotrophic lateral sclerosis 5, juvenile	602099	Arthrogryposis renal dysfunction and cholestasis Types 1 and 2	208085, 613404
Amyotrophic lateral sclerosis 8	608627	Ataxia Telangiectasia	208900
Amyotrophic lateral sclerosis 9	611895	Atrial Septal Defect (ASD) 7 with or without motor conduction defects	108900
Amyotrophic Lateral Sclerosis Frontotemporal Dementia	105550	Atypical Haemolytic Uraemic Syndrome (aHUS) type 1	235400
Anauxetic Dysplasia	607095	Atypical Haemolytic Uraemic Syndrome (aHUS) type 2	612922
Andersen Cardiodysrhythmic Periodic Paralysis	170390	Atypical Haemolytic Uraemic Syndrome (aHUS) type 3	612923
Anderson Fabry Disease	301500	Atypical Haemolytic Uraemic Syndrome (aHUS) type 4	612924
Androgen Insensitivity Syndrome	300068	Atypical Haemolytic Uraemic Syndrome (aHUS) type 5	612925
Angelman Syndrome (UBE3A gene only)	105830	Atypical Haemolytic Uraemic Syndrome (aHUS) type 6	612926
Aniridia	106210	Atypical Haemolytic Uraemic Syndrome (aHUS) type 7	615008
Antithrombin III Deficiency (AT3D)	613118	Auditory Neuropathy and Optic Atrophy (ANOA)	617717
Apert syndrome, OMIM	101200	Autosomal Dominant Acute Necrotizing Encephalopathy	608033
Aplastic anaemia - severe*		Autosomal dominant Dyskeratosis Congenita 1 (DKCA1) due to TERC mutation	127550
Argininosuccinic Aciduria	207900	Autosomal dominant familial exudative vitreoretinopathy Types 1, 4 and 5	133780, 613310, 601813

Description	OMIM number	Description	OMIM number
Autosomal Dominant Polycystic Kidney Disease 1 (APKD1)	173900	Bartter Syndrome Types 1, 2, 3, 4a & 4b (BARTS)	601678, 241200, 607364, 602522, 613090
Autosomal Dominant Retinitis Pigmentosa (AP37)	611131	Beare Stevenson syndrome	123790
Autosomal Dominant Retinitis Pigmentosa Type 4	613731	Beckwith-Wiedemann Syndrome caused by a mutation in the CDKN1C gene or inheritance of a chromosome translocation, deletion or duplication affecting the chromosome 11 Beckwith Wiedemann syndrome region	
Autosomal dominant vitreoretinochoroidopathy	193220	Benign Chronic Pemphigus (BCPM)	169600
Autosomal recessive bestrophinopathy	611809	Beta Thalassaemia*	141900
Autosomal recessive congenital hyperinsulinism	256450, 601820	Bethlem Myopathy 1 (BTHLM1)	158810
Autosomal Recessive Deafness 77 (DFNB77)	613079	Bilateral Frontoparietal Polymicrogyria (BFPP)	606854
Autosomal recessive Deafness Type 1A (DFNB1A)	220290	Birt-Hogg-Dubé Syndrome	135150
Autosomal Recessive Dopa Responsive Dystonia	233910	Blepharophimosis, Ptosis & Epicanthus Inversus Syndrome Types 1 & 2 (BPES 1 & 2)	110100
Autosomal Recessive Mitochondrial Complex 1 Deficiency (Complex 1 Deficient Leigh Syndrome)	252010	Bloom Syndrome	210900
Autosomal Recessive Severe Combined Immunodeficiency with Bilateral Sensorineural Deafness (ARSCIDBSD)	267500	Branchio-oculo-facial Syndrome (BOFS)	113620
Autsomal recessive Epidermolysis Bullosa Dystrophica (RDEB)	226600	Branchio-Oto-Renal Syndrome 1 (BOR1)	113650
Axenfeld-Rieger syndrome Types 1 and 3	180500, 602482	BRCA 1 (increased susceptibility to breast cancer)	113705
Bailey-Bloch Congenital Myopathy (BBCM)	255995	Breast Ovarian Cancer Familial Susceptibility (BRCA2)	612555, 600185
BAP1 tumour predisposition syndrome (BAP1-TPDS)	614327	Brooke-Spiegler Syndrome (BSS)	605041
Bardet-Biedl Syndrome (BBS1)	209900	Brugada Syndrome 1 (Sudden Unexplained Nocturnal Death Syndrome (SUNDS))	601144
Bardet-Biedl Syndrome 10 (BBS10)	615987	Calpainopathy	253600
Bare Lymphocyte Syndrome, Type II, complementation groups A-E	209920	Campomelic Dysplasia	114290
Barth Syndrome	302060	Canavan Disease	271900
Bartsocas-Papas Syndrome (Popliteal Pterygium syndrome, lethal type)	263650		

Description	OMIM number	Description	OMIM number
Cantu Syndrome, Hypertrichotic Osteochondrodysplasia	239850	Cardiomyopathy, dilated1MM/LVNC10	OMIM #615396
Capillary Malformation-Arteriovenous Malformation Type 1 (CM-AVM1)	608354	Carney Complex	160980
Capillary Malformation-Arteriovenous Malformation Type 2 (CM-AVM2)	618196	Carnitine Acylcarnitine Translocase Deficiency (CACT)	212138
Cardiomyopathy, dilated 1AA, with or without LVNC	612158	Cartilage-Hair Hypoplasia	250250
Cardiomyopathy, dilated 1BB	612877	Cartilage-hair hypoplasia spectrum	157660
Cardiomyopathy, dilated 1CC	613122	Cataract 1 (CTRCT1)	116200
Cardiomyopathy, dilated 1DD	613172	Cataract 2 (CTRCT2)	604307
Cardiomyopathy, dilated 1E	601154	Cataract 4 (CTRCT4)	115700
Cardiomyopathy, dilated 1FF	613286	Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT1)	604772
Cardiomyopathy, dilated 1I	604765	Catecholaminergic Polymorphic Ventricular Tachycardia type 3 (CPVT3)	614021
Cardiomyopathy, dilated 1R/LVNC4	613424	Catecholaminergic Polymorphic Ventricular Tachycardia type 4 (CPVT4)	614916
Cardiomyopathy, dilated 1W	611407	Catecholaminergic Polymorphic Ventricular Tachycardia type 5 with or without muscle weakness (CPVT5)	615441
Cardiomyopathy, dilated 1Z	611879	Catecholaminergic Polymorphic Ventricular Tachychardia 2 (CPVT2)	611938
Cardiomyopathy, dilated 2A	611880	Central Core Disease of Muscle (CCD)	117000
Cardiomyopathy, dilated 3B	302045	Centronuclear Myopathy (CNM1)	160150
Cardiomyopathy, dilated, 1A; CMD1A	115200	Cerebellar Ataxia, Intellectual Disability and Dysequilibrium Syndrome Type 1	224050
Cardiomyopathy, dilated, 1D; CMD1D	601494	Cerebellar Ataxia, Intellectual Disability and Dysequilibrium Syndrome Type 2	610185
Cardiomyopathy, dilated, 1DD (CMD1DD)	613172	Cerebellar Ataxia, Intellectual Disability and Dysequilibrium Syndrome Type 3	613227
Cardiomyopathy, dilated, 1P; CMD1P	609909	Cerebellar Ataxia, Intellectual Disability and Dysequilibrium Syndrome Type 4	615268
Cardiomyopathy, dilated, 1S; CMD1S	613426	Cerebral Autosomal Dominant Arteriopathy with Sub cortical infarcts and Leukoencephalopathy (CADASIL)	125310
Cardiomyopathy, dilated, 1Y; CMD1Y	611878	Cerebral Cavernous Malformations (CCM)	116860
Cardiomyopathy, Dilated, Type 1G (CMD1G)	604145	Cerebral Cavernous Malformations 3 (CCM3)	603285
Cardiomyopathy, Dilated, Type 1HH (CMD1HH)	613881		

Description	OMIM number	Description	OMIM number
Cerebral Creatine Deficiency Syndrome 1 (CCDS1)	300352	Charcot-Marie-Tooth disease, axonal, type 2P (CMT2P)	614436
Cerebral Creatine Deficiency Syndrome 2 (CCDS2)	612736	Charcot-Marie-Tooth Disease, Type 4A (CMT4A)	214400
Cerebral Creatine Deficiency Syndrome 3 (CCDS3)	612718	Charcot-Marie-Tooth Disease, Type 4B1 (CMT4B1)	601382
Cerebro-oculo-facial-skeletal syndrome Type 1 (COFS1)	214150	Charcot-Marie-Tooth Disease, Type 4B2 (CMT4B2)	604563
Cerebro-oculo-facial-skeletal syndrome Type 2 (COFS2)	610756	Charcot-Marie-Tooth Disease, Type 4B3 (CMT4B3)	615284
Cerebro-oculo-facial-skeletal syndrome Type 3 (COFS3)	616570	Charcot-Marie-Tooth Disease, Type 4C (CMT4C)	601596
Cerebro-oculo-facial-skeletal syndrome type 4 (COFS4)	610758	Charcot-Marie-Tooth Disease, Type 4D (CMT4D)	601455
Ceroid Lipofuscinosis, Neuronal, type 1 (CLN1)	256730	Charcot-Marie-Tooth Disease, Type 4F (CMT4F)	614895
Ceroid Lipofuscinosis, Neuronal, type 1 (CLN1)	256740	Charcot-Marie-Tooth Disease, Type 4G (CMT4G)	605285
Ceroid Lipofuscinosis, Neuronal, type 10 (CLN10)	610127	Charcot-Marie-Tooth Disease, Type 4H (CMT4H)	609311
Ceroid Lipofuscinosis, Neuronal, Type 2 (CLN2)	204500	Charcot-Marie-Tooth Disease, Type 4K (CMT4K)	616684
Ceroid Lipofuscinosis, Neuronal, type 5 (CLN5)	256731	CHARGE Syndrome	214800
Ceroid Lipofuscinosis, Neuronal, type 6 (CLN6)	601780	Chondrodysplasia Punctata	302950
Ceroid Lipofuscinosis, Neuronal, type 7 (CLN7)	610951	Choroideraemia	303100
Ceroid Lipofuscinosis, Neuronal, type 8 (CLN8)	600143	Christianson syndrome	300243
CFHR5 Deficiency	614809	Chromosomal rearrangements (various)	
Charcot Marie Tooth Disease (x-linked)	302800	Chudley-McCullough Syndrome (CMCS)	604213
Charcot Marie Tooth Disease Type 2A2A (CMT2A2A)	609260	Citrullinaemia type 1	215700
Charcot Marie Tooth Disease Type 2A2B	617087	Classical Ehlers Danlos Syndrome	130000, 130010
Charcot Marie Tooth Disease, demyelinating type 1A (CMT1A)	118220	Cleidocranial Dysplasia (CCD)	119600
Charcot Marie Tooth type 1B (CM1B)	118200	Cockayne Syndrome type A and B	216400, 133540
Charcot Marie Tooth type 1C (CM1C)	601098	Coenzyme Q10 Deficiency, Primary, 1	607426
Charcot Marie Tooth type 1D (CM1D)	607678	Coffin-Lowry Syndrome (CLS)	303600
Charcot Marie Tooth type 1E (CM1E)	118300	Cohen Syndrome (COH1)	216550
Charcot Marie-Tooth Disease, Type 4E (CMT4E)	602253	Combined immunodeficiency, X-linked, moderate (XLR)	312863
Charcot-Marie Tooth Disease, Type 4J (CMT4J)	611228	Combined Oxidative Phosphorylation Deficiency 1 (COXPD1)	609060

Description	OMIM number	Description	OMIM number
Combined Oxidative Phosphorylation Deficiency 10 (COXPD10)	614702	Combined Oxidative Phosphorylation Deficiency 25 (COXPD25)	616430
Combined Oxidative Phosphorylation Deficiency 11 (COXPD11)	614922	Combined Oxidative Phosphorylation Deficiency 26 (COXPD26)	616539
Combined Oxidative Phosphorylation Deficiency 12 (COXPD12)	614924	Combined Oxidative Phosphorylation Deficiency 27 (COXPD27)	616672
Combined Oxidative Phosphorylation Deficiency 13 (COXPD13)	614932	Combined Oxidative Phosphorylation Deficiency 28 (COXPD28)	616794
Combined Oxidative Phosphorylation Deficiency 14 (COXPD14)	614946	Combined Oxidative Phosphorylation Deficiency 29 (COXPD29)	616811
Combined Oxidative Phosphorylation Deficiency 15 (COXPD15)	614947	Combined Oxidative Phosphorylation Deficiency 3 (COXPD3)	610505
Combined Oxidative Phosphorylation Deficiency 16 (COXPD16)	615395	Combined Oxidative Phosphorylation Deficiency 30 (COXPD30)	616974
Combined Oxidative Phosphorylation Deficiency 17 (COXPD17)	615440	Combined Oxidative Phosphorylation Deficiency 31 (COXPD31)	617228
Combined Oxidative Phosphorylation Deficiency 18 (COXPD18)	615578	Combined Oxidative Phosphorylation Deficiency 32 (COXPD32)	617664
Combined Oxidative Phosphorylation Deficiency 19 (COXPD19)	615595	Combined Oxidative Phosphorylation Deficiency 33 (COXPD33)	617713
Combined Oxidative Phosphorylation Deficiency 2 (COXPD2)	610498	Combined Oxidative Phosphorylation Deficiency 34 (COXPD34)	617872
Combined Oxidative Phosphorylation Deficiency 20 (COXPD20)	615917	Combined Oxidative Phosphorylation Deficiency 35 (COXPD35)	617873
Combined Oxidative Phosphorylation Deficiency 21 (COXPD21)	615918	Combined Oxidative Phosphorylation Deficiency 36 (COXPD36)	617950
Combined Oxidative Phosphorylation Deficiency 22 (COXPD22)	616045	Combined Oxidative Phosphorylation Deficiency 4 (COXPD4)	610678
Combined Oxidative Phosphorylation Deficiency 23 (COXPD23)	616198	Combined Oxidative Phosphorylation Deficiency 5 (COXPD5)	611719
Combined Oxidative Phosphorylation Deficiency 24 (COXPD24)	616239	Combined Oxidative Phosphorylation Deficiency 7 (COXPD7)	613559

Description	OMIM number	Description	OMIM number
Combined Oxidative Phosphorylation Deficiency 8 (COXPD8)	614096	Cone Rod Dystrophy 9 (CORD9)	612775
Combined Oxidative Phosphorylation Deficiency 9 (COXPD9)	614582	Congenital Adrenal Hyperplasia (21 hydroxylase deficiency)	201910
Combined Pituitary Hormone Deficiency Type 1	63038	Congenital Cataracts	601885
Combined Pituitary Hormone Deficiency Type 2	262600	Congenital Contractual Arachnodactyly (Beals Syndrome)	121050
Combined Pituitary Hormone Deficiency Type 3	600577	Congenital Deafness with inner ear agenesis, microtia and microdontia	610706
Combined Pituitary Hormone Deficiency Type 4	602146	Congenital Disorder of Glycosylation type 1a (CDG1A)	212065
Combined Pituitary Hormone Deficiency Type 5	601802	Congenital Disorder of Glycosylation type 1D (CDG1D)	601110
Combined Pituitary Hormone Deficiency Type 6	600037	Congenital Dyserythropoietic Anaemia types 1a, 1b and 2	224120, 615631, 224100
Cone Rod Dystrophy 10 (CORD10)	610283	Congenital Fibrosis of the extraocular muscles (CFEOM1 and CFEOM3B)	135700
Cone Rod Dystrophy 11 (CORD11)	610381	Congenital Heart Defects, Multiple Types 6 (CHTD6) (NB this relates to the autosomal recessive type of the condition only)	613854
Cone Rod Dystrophy 12 (CORD12)	612657	Congenital Hemidysplasia with Ichthyosiform Erythrodema and Limb Defects (CHILD) syndrome	308050
Cone Rod Dystrophy 13 (CORD13)	608194	Congenital hereditary cataract, type 10 (CTRCT10)	600881
Cone Rod Dystrophy 14 (CORD14)	602093	Congenital hereditary cataract, type 11 (CTRCT11)	610623
Cone Rod Dystrophy 15 (CORD15)	613660	Congenital hereditary cataract, type 12 (CTRCT12)	611597
Cone Rod Dystrophy 16 (CORD16)	614500	Congenital hereditary cataract, type 15 (CTRCT15)	615274
Cone Rod Dystrophy 18 (CORD18)	615374	Congenital hereditary cataract, type 16 (CTRCT16)	613763
Cone Rod Dystrophy 19 (CORD19)	615860	Congenital hereditary cataract, type 17 (CTRCT17)	611544
Cone Rod Dystrophy 2 (CORD2)	120970	Congenital hereditary cataract, type 18 (CTRCT18)	610019
Cone Rod Dystrophy 20 (CORD20)	615973	Congenital hereditary cataract, type 19 (CTRCT19)	615277
Cone Rod Dystrophy 21 (CORD 21)	616502	Congenital hereditary cataract, type 21 (CTRCT21)	610202
Cone Rod Dystrophy 3 (CORD3)	604232	Congenital hereditary cataract, type 22 (CTRCT22)	609741
Cone Rod Dystrophy 5 (CORD5)	600977	Congenital hereditary cataract, type 23 (CTRCT23)	610425
Cone Rod Dystrophy 6 (CORD6)	601777		
Cone Rod Dystrophy 7 (CORD7)	603349		

Description	OMIM number	Description	OMIM number
Congenital hereditary cataract, type 30 (CTRCT30)	116300	Cutis Laxa, autosomal recessive, type IB (ARCL1B)	614437
Congenital hereditary cataract, type 33 (CTRCT33)	611391	Cutis Laxa, autosomal recessive, type IC (ARCL1C)	613177
Congenital hereditary cataract, type 34 (CTRCT34)	612968	Cutis Laxa, autosomal recessive, type IIA (ARCL2A)	219200
Congenital hereditary cataract, type 38 (CTRCT38)	614691	Cutis Laxa, autosomal recessive, type IIB; ARCL2B	612940
Congenital hereditary cataract, type 39 (CTRCT39)	615188	Cutis Laxa, autosomal recessive, type IIC (ARCL2C),	617402
Congenital hereditary cataract, type 40 (CTRCT40)	302200	Cutis Laxa, autosomal recessive, type IID (ARCL2D)	617403
Congenital hereditary cataract, type 44 (CTRCT44)	616509	Cutis Laxa, autosomal recessive, type IIIA (ARCL3A)	219150
Congenital hereditary cataract, type 6 (CTRCT6)	116600	Cutis Laxa, autosomal recessive, type IIIB (ARCL3B)	614438
Congenital hereditary cataract, type 9 (CTRCT9)	604219	Cystic Fibrosis (CF)	219700
Congenital hypomyelinating neuropathy 1	605253	Czech Dysplasia, metatarsal type also known as Progressive pseudorheumatoid dysplasia with hypoplastic toes	609162
Congenital hypomyelinating neuropathy 2	618184	D-bifunctional protein deficiency	261515
Congenital hypomyelinating neuropathy 3 (CHN3)	618186	Danon Disease	300257
Congenital Mitochondrial Encephalomyopathy	500002	Dehydrated hereditary stomatocytosis	194380
Congenital stationary night blindness Type 1A (CSNB1A)	310500	Dentatorubral-Pallidoluysian Atrophy (DRPLA)	125370
Conradi-Hunermann-Happle Syndrome	302960	Denys-Drash Syndrome (DDS)	194080
Convulsions, Familial Infantile, with Paroxysmal Choreoathetosis,	602066	Desbuquois Dysplasia 1 (DBQD1)	251450
Cowden syndrome (CS)/PTEN Hamartoma Tumour Syndrome (PHTS)	601728, 158350, 153480, 605309	Developmental and Epileptic Encephalopathy (DEE3)	609304
Craniofrontonasal syndrome (CFNS)	304110	Developmental and Epileptic Encephalopathy 12 (DEE12)	613722
Crigler-Najjar Syndrome Type 1 (CN1)	218800	Developmental and Epileptic Encephalopathy 15 (DEE15)	615006
Crouzon Syndrome	123500	Developmental and Epileptic Encephalopathy 16 (DEE16)	615338
Crouzon with acanthosis nigrans syndrome	612247	Developmental and Epileptic Encephalopathy 18 (DEE18)	615476
Currarino Syndrome	176450	Developmental and Epileptic Encephalopathy 21 (DEE21)	615833
Cutis Laxa, autosomal dominant 1 (ADCL1)	123700	Developmental and Epileptic Encephalopathy 23 (DEE23)	615859
Cutis Laxa, autosomal recessive, type IA (ARCL1A)	219100	Developmental and Epileptic Encephalopathy 25 (DEE25)	615905

Description	OMIM number	Description	OMIM number
Developmental and Epileptic Encephalopathy 28 (DEE28)	616211	Developmental and Epileptic Encephalopathy, type 4 (DEE4)	612164
Developmental and Epileptic Encephalopathy 29 (DEE29)	616339	Developmental and Epileptic Encephalopathy, type 41 (DEE41)	617105
Developmental and Epileptic Encephalopathy 34 (DEE34)	616645	Developmental and Epileptic Encephalopathy, type 42 (DEE42)	617106
Developmental and Epileptic Encephalopathy 35 (DEE35)	616647	Developmental and Epileptic Encephalopathy, type 43 (DEE43)	617113
Developmental and Epileptic Encephalopathy 37 (DEE37)	616981	Developmental and Epileptic Encephalopathy, type 44 (DEE44)	617132
Developmental and Epileptic Encephalopathy 38 (DEE38)	617020	Developmental and Epileptic Encephalopathy, type 45 (DEE45)	617153
Developmental and Epileptic Encephalopathy 39 (DEE39)	612949	Developmental and Epileptic Encephalopathy, type 46 (DEE46)	617162
Developmental and Epileptic Encephalopathy 40 (DEE40)	617065	Developmental and Epileptic Encephalopathy, type 47 (DEE47)	617166
Developmental and Epileptic Encephalopathy 48 (DEE48)	617276	Developmental and Epileptic Encephalopathy, type 49 (DEE49)	617281
Developmental and Epileptic Encephalopathy 7 (DEE7)	613720	Developmental and Epileptic Encephalopathy, type 5 (DEE5)	613477
Developmental and Epileptic Encephalopathy, type 1 (DEE1)	308350	Developmental and Epileptic Encephalopathy, type 50 (DEE50)	616457
Developmental and Epileptic Encephalopathy, type 11 (DEE11)	613721	Developmental and Epileptic Encephalopathy, type 51 (DEE51)	617339
Developmental and Epileptic Encephalopathy, type 13 (DEE13)	614558	Developmental and Epileptic Encephalopathy, type 52 (DEE52)	617350
Developmental and Epileptic Encephalopathy, type 14 (DEE14)	614959	Developmental and Epileptic Encephalopathy, type 53 (DEE53)	617389
Developmental and Epileptic Encephalopathy, type 17 (DEE17)	615473	Developmental and Epileptic Encephalopathy, type 54 (DEE54)	617391
Developmental and Epileptic Encephalopathy, type 19 (DEE19)	615744	Developmental and Epileptic Encephalopathy, type 55 (DEE55)	617599
Developmental and Epileptic Encephalopathy, type 2 (DEE2)	300672	Developmental and Epileptic Encephalopathy, type 56 (DEE56)	617665
Developmental and Epileptic Encephalopathy, type 24 (DEE24)	615871	Developmental and Epileptic Encephalopathy, type 57 (DEE57)	617771
Developmental and Epileptic Encephalopathy, type 26 (DEE26)	616056	Developmental and Epileptic Encephalopathy, type 58 (DEE58)	617830
Developmental and Epileptic Encephalopathy, type 27 (DEE27)	616139	Developmental and Epileptic Encephalopathy, type 59 (DEE59)	617904
Developmental and Epileptic Encephalopathy, type 30 (DEE30)	616341	Developmental and Epileptic Encephalopathy, type 60 (DEE60)	617929
Developmental and Epileptic Encephalopathy, type 31 (DEE31)	616346	Developmental and Epileptic Encephalopathy, type 61 (DEE61)	617933
Developmental and Epileptic Encephalopathy, type 32 (DEE32)	616366	Developmental and Epileptic Encephalopathy, type 62 (DEE62)	617938
Developmental and Epileptic Encephalopathy, type 33 (DEE33)	616409	Developmental and Epileptic Encephalopathy, type 63 (DEE63)	617976
Developmental and Epileptic Encephalopathy, type 36 (DEE36)	300884	Developmental and Epileptic Encephalopathy, type 64 (DEE64)	618004

Description	OMIM number	Description	OMIM number
Developmental and Epileptic Encephalopathy, type 65 (DEE65)	618008	Developmental and Epileptic Encephalopathy, type 9 (DEE9)	300088
Developmental and Epileptic Encephalopathy, type 66 (DEE66)	618067	Developmental and Epileptic Encephalopathy, type 90 (DEE90)	301058
Developmental and Epileptic Encephalopathy, type 67 (DEE67)	618141	Developmental and Epileptic Encephalopathy, type 91 (DEE91)	617711
Developmental and Epileptic Encephalopathy, type 68 (DEE68)	618201	Developmental and Epileptic Encephalopathy, type 92 (DEE92)	617829
Developmental and Epileptic Encephalopathy, type 69 (DEE69)	618285	Developmental and Epileptic Encephalopathy, type 93 (DEE93)	618012
Developmental and Epileptic Encephalopathy, type 6B (DEE6B) Non Dravet	619317	Developmental and Epileptic Encephalopathy, type 94 (DEE94)	615369
Developmental and Epileptic Encephalopathy, type 70 (DEE70)	618298	Developmental and Epileptic Encephalopathy, type 96 (DEE96)	619340
Developmental and Epileptic Encephalopathy, type 71 (DEE71)	618328	Diamond Blackfan Anaemia 1*	105650
Developmental and Epileptic Encephalopathy, type 72 (DEE72)	618374	Diarrhea 1, Secretory Chloride, Congenital (DIAR1)	214700
Developmental and Epileptic Encephalopathy, type 73 (DEE73)	618379	Diarrhea 10, Protein Losing Enteropathy, type (DIAR 10)	618183
Developmental and Epileptic Encephalopathy, type 74 (DEE74)	618396	Diarrhea 11, Malabsorptive, Congenital (DIAR11)	618662
Developmental and Epileptic Encephalopathy, type 75 (DEE75)	618437	Diarrhea 2, with Microvillus Atrophy (DIAR2)	251850
Developmental and Epileptic Encephalopathy, type 76 (DEE76)	618468	Diarrhea 3, Secretory Sodium, Congenital Syndromic (DIAR3)	270420
Developmental and Epileptic Encephalopathy, type 77 (DEE77)	618548	Diarrhea 5, with Tufting Enteropathy, Congenital (DIAR5)	613217
Developmental and Epileptic Encephalopathy, type 78 (DEE78)	618557	Diarrhea 8, Secretory Sodium, Congenital (DIAR8)	616868
Developmental and Epileptic Encephalopathy, type 79 (DEE79)	618559	Diarrheoa 5 with tufting enteropathy congenital (DIAR5)	613217
Developmental and Epileptic Encephalopathy, type 8 (DEE8)	300607	Dihydrolipoamide Dehydrogenase Deficiency (DLDD)	246900
Developmental and Epileptic Encephalopathy, type 80 (DEE80)	618580	Distal Hereditary Motor Neuropathy type IIB	608634
Developmental and Epileptic Encephalopathy, type 81 (DEE81)	618663	Distal Renal Tubular Acidosis with progressive nerve deafness	602722, 267300
Developmental and Epileptic Encephalopathy, type 82 (DEE82)	618721	Dominant Dystrophic Epidermolysis Bullosa	131750
Developmental and Epileptic Encephalopathy, type 83 (DEE83)	618744	Donnai-Barrow Syndrome	222448
Developmental and Epileptic Encephalopathy, type 84 (DEE84)	618792	Donohue Syndrome	246200
Developmental and Epileptic Encephalopathy, type 85 (DEE85)	301044	Dopamine Responsive Dystonia (DRD)	128230
Developmental and Epileptic Encephalopathy, type 87 (DEE87)	618916	Downs Syndrome	190685
Developmental and Epileptic Encephalopathy, type 89 (DEE89)	619124	Doyne honeycomb retinal dystrophy (DHRD)	126600

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Dravet Syndrome (DEE6A)	607208	Epidermolysis bullosa simplex, with pyloric atresia (EBSPA)	612138
Duane-radial ray syndrome (Okihiro syndrome, acro-renal-ocular syndrome, SALL4-related Holt Oram syndrome)	607323	Epidermolysis bullosa, junctional, with pyloric stenosis or pyloric atresia	226730
Dyskeratosis congenita (Male embryos only)	305000	Epidermolysis bullosa, lethal acantholytic	609638
Dyskeratosis Congenita types A2 and B4, due to TERT mutation	613989	Epidermolytic hyperkeratosis (EHK)	113800
Dystonia 1 Torsion Autosomal Dominant (DYT1)	128100	Epiphyseal Dysplasia, Multiple, 1 (EDM1)	132400
Ectodermal dysplasia / skin fragility syndrome	604536	Epiphyseal Dysplasia, Multiple, 2 (EDM2)	600204
Ectrodactyly, Ectodermal Dysplasia and Cleft Lip/Palate syndrome 3 (EEC3)	604292	Epiphyseal Dysplasia, Multiple, 3 (EDM3)	600969
Ectrodactyly, Ectodermal Dysplasia, Clefting Syndrome (EEC)	129900	Epiphyseal Dysplasia, Multiple, 4 (EDM4)	226900
Ehlers-Danlos periodontal type 1 (EDSPD1)	130080	Epiphyseal Dysplasia, Multiple, 6 (EDM6)	614135
Ehlers-Danlos periodontal type 2 (EDSPD2)	617174	Epiphyseal Dysplasia, Multiple, 7 (EDM7)	617719
Ehlers-Danlos Type IV	130050	Episodic Ataxia Type 2 (EA2)	108500
Elastin (ELN)-related Supravalvular Aortic Stenosis	185500	Episodic Kinesigenic Dyskinesia type1 (EKD1)	128200
Ellis-Van Crevald Syndrome	225500	Facioscapulohumeral Muscular Dystrophy (FSHD1)	158900
Emery-Dreifuss Muscular Dystrophy (x-linked) (EDMD) (Male embryos only)	310300	Facioscapulohumeral Muscular Dystrophy Type 2 (FSHD2)	158901
Emery-Dreifuss muscular dystrophy 4 (EDMD4)	612998	Factor XIII deficiency	613225
Emery-Dreifuss muscular dystrophy 5 (EDMD5)	612999	Familial Adenomatous polyposis 1 (FAP1)	175100
Emery-Dreifuss muscular dystrophy 6 X-Linked (EDMD6)	300696	Familial Adenomatous Polyposis 2 (FAP2) (MUTYH-associated polyposis)	608456
Emery-Dreifuss muscular dystrophy 7 (EDMD7)	614302	Familial Creutzfeldt-Jakob disease (fCJD),	123400
Emery-Dreifuss Muscular Dystrophy type 2 - for cases where there is proven evidence of mosaicism in the blood or as a result of a second affected child	181350	Familial Dysautonomia	223900
Emery-Dreifuss Muscular Dystrophy type 3	616516	Familial Fatal Insomnia	600072
Epidermolysis bullosa simplex, with muscular dystrophy (EBS-MD)	226670	Familial Haemophagocytic Lymphohistiocytosis type 3 (FHL3)	608898

Description	OMIM number	Description	OMIM number
Familial Haemophagocytic Lymphohistiocytosis type 4	603552	Fanconi Anaemia, Complementation Group L	614083
Familial Hemophagocytic Lymphohistiocytosis (FHL)	603553	Fanconi Anaemia, Complementation Group O	613390
Familial Hemophagocytic Lymphohistiocytosis 5 (FHL5)	613101	Fanconi Anaemia, Complementation Group P	613951
Familial Hypertrophic Cardiomyopathy 4 (CMH4)	115197	Fanconi Anaemia, Complementation Group Q	615272
Familial Hypertrophic Cardiomyopathy type 1, 3, 7 and 10 (CMH1 , CMH3, CMH7, CMH10)	192600, 115196, 613690, 608758	Fanconi Anaemia, Complementation Group R	617244
Familial Infantile Myoclonic Epilepsy (FIME)	605021	Fanconi Anaemia, Complementation Group S	617883
Familial Juvenile Hyperuricemic Nephropathy 1 (HNFJ1)	162000	Fanconi Anaemia, Complementation Group T	616435
Familial Myelodysplastic Syndrome	614286	Feingold syndrome 1 (FGLDS1)	164280
Familial Paranganglioma Syndrome (PGL1)	168000	Fetal Akinesia Deformation Sequence (Pena-Shokeir syndrome type 1)	208150
Familial Partial Lipodystrophy Type 3	604367	Fibrodysplasia Ossificans Progressiva (FOP)	OMIM #135100
Familial Partial Lipodystrophy Type 4	613877	Focal Dermal Hypoplasia (FDH)	305600
Familial Partial Lipodystrophy Type 6	615980	Focal Segmental Glomerulosclerosis 7 (FSGS7)	616002
Familial thoracic aortic aneurysm 6	611788	Focal Segmental Glomerulosclerosis Type 1	603278
Fanconi anaemia type A (FANCA)	227650	Focal Segmental Glomerulosclerosis Type 2	603965
Fanconi anaemia type C (FANCC)*	227645	Focal Segmental Glomerulosclerosis Type 5	613237
Fanconi Anaemia type N	610832	Focal Segmental Glomerulosclerosis Type 6	614131
Fanconi Anaemia, Complementation Group B	300514	Focal Segmental Glomerulosclerosis Type 8	615032
Fanconi Anaemia, Complementation Group D1	605724	Focal Segmental Glomerulosclerosis Type 9	616220
Fanconi Anaemia, Complementation Group D2	227646	Fontaine Progeroid Syndrome (FPS)	612289
Fanconi Anaemia, Complementation Group E	600901	Fragile X Syndrome (FRAX)	300624
Fanconi Anaemia, Complementation Group F	603467	Fragile XE syndrome (FRAXE)	309548
Fanconi Anaemia, Complementation Group G	614082	Fraser Syndrome	219000
Fanconi Anaemia, Complementation Group I	609053	Friedreich Ataxia 1 (FRDA)	229300
Fanconi Anaemia, Complementation Group J	609054	Frontometaphyseal Dysplasia	305620

Description	OMIM number	Description	OMIM number
Frontotemporal Dementia	600274	Glycogen Storage Disease Type 3	232400
Frontotemporal dementia and/or amyotrophic lateral sclerosis 2	615911	Glycogen Storage Disease Type 4, (GSD4)	232500
Frontotemporal dementia and/or Amyotrophic lateral sclerosis 3	616437	Glycogen Storage Disease Type Ia	232200
Frontotemporal dementia and/or Amyotrophic lateral sclerosis 4	616439	Glycogen storage disease V (GSD5)	232600
Galactosaemia	230400	Glycogen storage disease VI (GSD6)	232700
Galactosialidosis (early infantile and adult / juvenile types) (GSL)	256540	Glycogen storage disease VII (GSD7)	232800
Gangliosidosis (GM1)	230500	Goiter, Multinodular 1, with or without Sertoli-Leydig cell tumours (MNG1)	138800
Gastrointestinal defects and immunodeficiency syndrome (GIDID)	243150	Gonadal mosaicism	
Gaucher Disease Type II	230900	Gorlin Syndrome	109400
Gaucher Disease Type III	231000	Greig Cephalopolysyndactyly (GCPS)	175700
Generalized epilepsy with febrile seizures plus, type 1 (GEFSP1)	604233	GRN-related Frontotemporal Lobar Degeneration with TDP43 inclusions	607485
Generalized epilepsy with febrile seizures plus, type 2 (GEFSP2)	604403	Haemoglobin SC disease	141900
Generalized epilepsy with febrile seizures plus, type 3 (GEFSP3)	607681	Haemophilia A (HEMA)	306700
Generalized epilepsy with febrile seizures plus, type 5, susceptibility to, (GEFSP5)	613060	Haemophilia B (HEMB)	306900
Geroderma Osteodysplasticum	231070	Harel-Yoon Syndrome, (HAYOS)	617183
Gerstmann-Straussler-Scheinker syndrome	137440	Heimler Syndrome 1	234580
Glanzmann Thrombasthenia	273800	Heimler Syndrome 2	616617
Glutaric Acidemia (aciduria)	231670	Hereditary Angioedema (HAE) Type I & Type II	106100
Glycogen Storage Disease II (Pompe Disease (early onset)) (GSD2)	232300	Hereditary Angioedema (HAE) Type III	610618
Glycogen storage disease IXa1 (GSD9A1)	306000	Hereditary diffuse gastric cancer (HDGC)	137215
Glycogen storage disease IXa2 (GSD9A2)	306000	Hereditary Emberger Syndrome	614038
Glycogen storage disease IXb (GSD9B)	261750	Hereditary Haemorrhagic Telangiectasia (HTT) or Rendu-Osler-Weber Syndrome	187300
Glycogen storage disease IXc (GSD9C)	613027	Hereditary Haemorrhagic Telangiectasia Type 2 (HHT2)	600376
Glycogen storage disease IXd (GSD9D)	300559	Hereditary Leiomyomatosis and Renal Cell Cancer (HLRCC)	150800
Glycogen storage disease type 1B	232220	Hereditary motor and sensory neuropathy, type IIc (HMSN2C)	606071

Description	OMIM number	Description	OMIM number
Hereditary Multiple Exostoses Type II	133701	Hyperphosphatasia with intellectual disability syndrome 2	614749
Hereditary Nonpolyposis Colorectal Cancer: Lynch Syndrome (for all subtypes)		Hyperphosphatasia with intellectual disability syndrome 3	614207
Hereditary Pancreatitis	167800	Hyperphosphatasia with intellectual disability syndrome 5	616025
Hereditary Sensory Neuropathy type 1A	162400	Hyperphosphatasia with intellectual disability syndrome 6	616809
Hermansky-Pudlak Syndrome 1 (HPS1)	203300	Hyperphosphatasia with intellectual disability syndrome 7	280000
Hermansky-Pudlak Syndrome 2 (HPS2)	608233	Hyperphosphatasia with Mental Retardation Syndrome 4 (HPMRS4)	615716
Hermansky-Pudlak Syndrome 3 (HPS3)	614072	Hypertrophic Neuropathy of Dejerine-Sottas (HNDS)	145900
Hermansky-Pudlak Syndrome 4 (HPS4)	614073	Hypocalcemia, autosomal dominant 1 (HYPOC1)	601198
Hermansky-Pudlak Syndrome 5 (HPS5)	614074	Hypocalcemia, autosomal dominant 2 (HYPOC2)	615361
Hermansky-Pudlak Syndrome 6 (HPS6)	614075	Hypochondroplasia	146000
Hermansky-Pudlak Syndrome 7 (HPS7)	614076	Hypophosphatasia (Infantile/perinatal lethal)	241500
Hermansky-Pudlak Syndrome 8 (HPS8)	614077	Hypophosphatasia, Adult (HPPA)	146300
Hirschsprung Disease 1 (HSCR1)	142623	Hypophosphatasia, Childhood (HPPC)	241510
Holt Oram Syndrome	142900	Hypophosphatemic Rickets (x-linked dominant) (XLHR)	307800
Homocystinuria	236200	Hypospadias (severe)	
Homozygous familial hypercholesterolaemia	143890	Hypotonia, infantile, with psychomotor retardation and characteristic facies 1 (IHPRF1)	615419
Huntington Disease (Huntington Chorea) (HD)	143100	Hypotonia, infantile, with psychomotor retardation and characteristic facies 2 (IHPRF2)	616801
Huntington disease-like (HDL1)	603218	Hypotonia, infantile, with psychomotor retardation and characteristic facies 3 (IHPRF3)	616900
Hutchinson-Gilford Progeria Syndrome (HGPS)	176670	Hypotonia, Parastremmatic Dwarfism	168400
Hyaline Fibromatosis Syndrome (HFS)	228600	Ichthyosis (x-linked) (XLI)	308100
Hyper IgM Syndrome - Hypogammaglobulinaemia*	308230	Ichthyosis 4B (Harlequin) (ARC14B)	242500
Hyper-IgE Recurrent Infection Syndrome, Autosomal Dominant	147060	Ichthyosis follicularis-alopecia-photophobia Syndrome; IFAP Syndrome 1 With or Without Bresheck Syndrome; (IFAP1)	308205

Description	OMIM number	Description	OMIM number
Ichthyosis with confetti	609165	Immunodeficiency 38 (IMD38)	616126
Ichthyosis, cyclic, with epidermolytic hyperkeratosis (ICEHK)	607602	Immunodeficiency 40	616433
Ichthyosis, Spastic Quadriplegia and Mental Retardation (ISQMR) Syndrome	614457	Immunodeficiency 41, with lymphoproliferation and autoimmunity (IMD41)	606367
Ichythosis hystrix of Curth-Macklin	146590	Immunodeficiency 42 (IMD42)	616622
Idiopathic Arterial Calcification of Infancy	208000	Immunodeficiency 42 (IMD42)	616622
Immunodeficiency 10 (IMD10)	612783	Immunodeficiency 43 (IMD43)	241600
Immunodeficiency 11A (IMD11A)	615206	Immunodeficiency 44 (IMD 44)	
Immunodeficiency 12 (IMD12)	615468	Immunodeficiency 46 (IMD46)	616740
Immunodeficiency 14 (IMD14)	615513	Immunodeficiency 47 (IMD47)	300972
Immunodeficiency 15B (IMD15B)	615592	Immunodeficiency 48 (IMD48)	269840
Immunodeficiency 17, CD3 gamma deficient	615607	Immunodeficiency 49 (IMD49)	617237
Immunodeficiency 18 (IMD18)	615615	Immunodeficiency 50 (IMD50)	300988
Immunodeficiency 18, SCID variant	615615	Immunodeficiency 51 (IMD51)	613953
Immunodeficiency 19	615617	Immunodeficiency 52 (IMD52)	617514
Immunodeficiency 20 (IMD20)	615707	Immunodeficiency 54 (IMD54)	609981
Immunodeficiency 21	614172	Immunodeficiency 55 (IMD55)	617827
Immunodeficiency 22 (IMD22)	615758	Immunodeficiency 56 (IMD56)	615207
Immunodeficiency 23 (IMD23)	615816	Immunodeficiency 57 (IMD57)	618108
Immunodeficiency 24	615897	immunodeficiency 58 (IMD58)	618131
Immunodeficiency 25 (IMD25)	610163	Immunodeficiency 63 with lymphoproliferation and autoimmunity (IMD63)	618495
Immunodeficiency 26, with or without neurologic abnormalities	615966	Immunodeficiency 64 (IMD64)	618534
Immunodeficiency 27A, mycobacteriosis (IMD27A)	209950	Immunodeficiency 8 (IMD8)	615401
Immunodeficiency 28, mycobacteriosis (IMD28)	614889	Immunodeficiency 9	612782
Immunodeficiency 31B	613796	Inclusion Body Myopathy with early onset Paget Disease and Frontotemporal Dementia 1 (IBMPFD1)	167320
Immunodeficiency 31C (IMD31C)	614162	Incontinentia Pigmenti (IP)	308300
Immunodeficiency 32B (IMD32B)	226990	Inflammatory Bowel Disease, Early-onset (IBD25)	612567
Immunodeficiency 33 (IMD33)	300636	Inflammatory Bowel Disease, Early-onset (IBD28)	613148
Immunodeficiency 34, mycobacteriosis, X-linked, (IMD34)	300645	Inherited Erythromelalgia (IEM)	133020
Immunodeficiency 35 (IMD35)	611521	Intellectual Disability, Autosomal Recessive 12	611090
Immunodeficiency 36 (IMD36)	616005	Intellectual Disability, X-linked 102 (MRX102)	300958
Immunodeficiency 37 (IMD37)	616098		

Description	OMIM number	Description	OMIM number
IPEX Syndrome (Immunodeficiency, Polyendocrinopathy and Enteropathy, X-Linked)	304790	Joubert syndrome type 9	612285
Isolated Growth Hormone Deficiency - type 1A (IGHD1A)	262400	Junctional Epidermolysis Bullosa (Herlitz type)	226700
Isolated Microphthalmia 2 (MCOP2)	610093	Juvenile Polyposis Syndrome (JPS)	174900
Isolated Sulfite Oxidase Deficiency (ISOD)	272300	Kabuki Syndrome Type 1	147920
Jackson Weiss syndrome, OMIM	123150	Kabuki Syndrome Type 2	300867
Jalili Syndrome	217080	Kearns Sayre Syndrome (KSS)/ Pearsons Marrow-Pancreas Syndrome (PMPS)	530000, 557000
Jervell and Lange-Nielsen Syndrome 1 (JLNS1)	220400	Keratosis Follicularis Spinulosa Decalvans, X-Linked (KFSDX)	308800
Jervell and Lange-Nielsen Syndrome 2 (JLNS2)	612347	Krabbe Disease	245200
Joubert syndrome type 1	213300	L–2-Hydroxyglutaric aciduria	236792
Joubert syndrome type 10	300804	Lacrimo-auriculo-dento-digital syndrome (LADD)	149730
Joubert syndrome type 13	614173	Langers Mesomelic Dysplasia (LMD)	249700
Joubert syndrome type 14	614424	Larsen Syndrome	150250
Joubert syndrome type 15	614464	Laryngo-onycho-cutaneous (LOC) Syndrome	245660
Joubert syndrome type 16	614465	Leber congenital amaurosis (LCA)	204000, 204100
Joubert syndrome type 17	614615	Leber congenital amaurosis type 10	611755
Joubert syndrome type 18	614815	Leber congenital amaurosis type 12	610612
Joubert syndrome type 2	608091	Leber congenital amaurosis type 13	612712
Joubert syndrome type 20	614970	Leber congenital amaurosis type 14	613341
Joubert syndrome type 21	615636	Leber congenital amaurosis type 15	613843
Joubert syndrome type 22	615665	Leber congenital amaurosis type 16	614186
Joubert syndrome type 23	616490	Leber congenital amaurosis type 17	615360
Joubert syndrome type 24	616654	Leber congenital amaurosis type 3	604232
Joubert syndrome type 25	616781	Leber congenital amaurosis type 4	604393
Joubert syndrome type 26	616784	Leber congenital amaurosis type 5	604537
Joubert syndrome type 3	608629	Leber congenital amaurosis type 6	613826
Joubert syndrome type 4	609583	Leber congenital amaurosis type 7 (autosomal recessive only)	613829
Joubert syndrome type 5	610188	Leber congenital amaurosis type 8	613835
Joubert syndrome type 6	610688	Leber congenital amaurosis type 9	608553
Joubert syndrome type 7	611560	Leber's Hereditary Optic Neuropathy (LHON) / Lebers Optic atrophy	535000
Joubert syndrome type 8	612291	Leigh Syndrome	256000
		Leigh Syndrome (Infantile Subacute Necrotising Encephalopathy) due to COX IV deficiency	185620

Description	OMIM number	Description	OMIM number
Leigh syndrome (subacute necrotising encephalopathy of childhood)	516000, 516002, 516005, 516006	Long QT Syndrome Types 1, 2, 3, 5 & 6	192500, 613688, 603830, 613695, 613693
Leigh Syndrome, French Canadian type (LSFC)	220111	Lowe Oculocerebrorenal Syndrome	309000
Lesch Nyhan syndrome	300322	Lubs X-linked mental retardation syndrome MRXSL (MECP2 Duplication syndrome)	300260
Lethal congenital contracture syndrome 7	616286	Lymphatic malformation 1, (LMPHM1) (Milroy Syndrome)	153100
Lethal Congenital Contracture syndrome type 1	253310	Lymphatic malformation 3, (LMPHM3)	613480
Lethal Congenital Contracture syndrome type 10	617022	Lymphatic malformation 4, (LMPHM4)	615907
Lethal Congenital Contracture syndrome type 11	617194	Lymphatic malformation 6, (LMPHM6)	616843
Lethal Congenital Contracture syndrome type 9	616503	Lymphatic malformation 7, (LMPHM7)	617300
Lethal Multiple Pterygium Syndrome (LMPS)	253290	Lymphoproliferative Syndrome, X-linked,1 (XLR)	308240
Leukaemia, acute myeloid, related to GATA2 mutation	601626	Mabry Syndrome (Hyperphosphatasia mental retardation syndrome-HPMRS), Type 1	239300
Leukocyte Adhesion Deficiency (Type I) (LAD)*	116920	Macrocephaly, dysmorphic facies, and psychomotor retardation, (MDFPMR)	617011
Leukoencephalopathy with Vanishing White Matter	603896	Mal De Meleda (MDM)	248300
Lewy body dementia	127750	Malignant Infantile Osteopetrosis	259700
Li-Fraumeni Syndrome 1	151623	Maple Syrup Urine Disorder (MSUD)	248600
Lissencephaly 2 (Norman-Roberts type) (LIS-2),	257320	Marfan Syndrome (MFS)	154700
Lissencephaly, type 3	611603	Meckel-Gruber Syndrome Types 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 and 11	249000, 603194, 607361, 611134, 611561, 612284, 267010, 613885, 614209, 614175 and 615397
Loeys-Dietz syndrome type 4	614816		
Loeys-Dietz syndrome types 1 and 2	609192, 610168		
Long Chain 3-hydroxyacyl-CoA Dehydrogenase Deficiency	609016		

Description	OMIM number	Description	OMIM number
Medium-Chain Acyl-CoA Dehydrogenase Deficiency	201450	Metabolic Crises, Recurrent, with Rhabdomyolysis, Cardiac Arrhythmias, and Neurodegeneration (MECRCN)	616878
Medullary Cystic Kidney Disease 2 (MCKD2) (also known as Autosomal Dominant Tubulointerstitial Kidney Disease due to Uromodulin Mutations (ADTKD-UMOD)	603860	Metachromatic Leukodystrophy (MLD)	250100
Megaloblastic Anemia due to Dihydrofolate Reductase Deficiency (DHFR)	613839	Metaphyseal Dysplasia without Hypotrichosis	250460
MEGDEL syndrome (3-Methylglutaconic Aciduria with Deafness, Encephalopathy, and Leigh-Like Syndrome)	614739	Metatropic dysplasia	156530
Melanoma Pancreatic Cancer Syndrome	606719	Methylmalonic Acidemia (MMA)	251000
Melanoma, cutaneous malignant, susceptibility to, 10 (CMM10)	615848	Methylmalonic Acidemia cb1A	251100
Melanoma, cutaneous malignant, susceptibility to, 2 (CMM2)	155601	Methylmalonic Acidemia cb1B	251110
Melanoma, cutaneous malignant, susceptibility to, 3 (CMM3)	609048	Methylmalonic Aciduria and Homocystinuria	277400
Melanoma-Astrocytoma Syndrome	155755	Micro Syndrome (WARBM)	600118
MELAS (Mitochondrial Encephalomyopathy, Lactic Acidosis and Stroke-like episodes)	540000	Microcephalic Osteodysplastic Primordial Dwarfism Type 1, (MOPD1)	210710
Melnick Needles Syndrome	309350	Microcephalic Osteodysplastic Primordial Dwarfism Type 2, (MOPD2)	210720
Menkes disease	309400	Microcephaly with or without chorioretinopathy, lymphoedema or mental retardation	152950
Mental Retardation, Autosomal Dominant 26; MRD26	615834	Microcephaly, seizures, and developmental delay (MCSZ)	613402
Mental Retardation, autosomal recessive 65	618109	Microcephaly, Short Stature and Polymicrogyria with or without seizures (MSSP)	614833
Mental Retardation, X-linked, Syndromic 34, caused by NONO gene mutation (MRXS34)	300967	Minicore Myopathy with External Ophthalmoplegia	255320
Mental Retardation, X-linked, syndromic, Claes-Jensen type (MRXSCJ)	300534	Mismatch Repair Cancer Syndrome (MMRCS)	276300
Mental retardation, X-linked, with panhypopituitarism	300123	Mismatch Repair Cancer Syndrome 2, (MMRCS2)	619096
Merosin Deficient Congenital Muscular Dystrophy type 1A (MDC1A) (also known as LAMA2-related Muscular Dystrophy)	607855	Mismatch Repair Cancer Syndrome 3, (MMRCS3)	619097

Description	OMIM number	Description	OMIM number
Multiple Endocrine Neoplasia type 2B (MEN 2B)	162300	Muscular dystrophy, limb-girdle, type 2C	253700
Multiple Endocrine Neoplasia Type I (MEN1)	131100	Muscular dystrophy, limb-girdle, type 2S	615356
Multiple Epiphyseal Dysplasia Type 5 (MED5)	607078	Muscular dystrophy-dystroglycanopathy (congenital with mental retardation), type B1	613155
Multiple Exostoses Type 1	133700	Muscular dystrophy-dystroglycanopathy (congenital with mental retardation), type B14	615351
Multiple Joint Dislocations, Short Stature and Craniofacial Dysmorphism with or without Congenital Heart Defects (JDSCD)	245600	Muscular dystrophy-dystroglycanopathy (congenital with mental retardation), type B2	613156
Multiple Lentigines Syndrome (LEOPARD Syndrome)	151100	Muscular dystrophy-dystroglycanopathy (congenital with mental retardation), type B3	613151
Multiple Pterygium Syndrome, Escobar variant, EVMPS	265000	Muscular dystrophy-dystroglycanopathy (congenital with mental retardation), type B6	608840
Multiple Sulfatase Deficiency (MSD)	272200	Muscular dystrophy-dystroglycanopathy (congenital with or without mental retardation), type B5	606612
Muscular Dystrophy (Becker) (BMD)	300376	Muscular dystrophy-dystroglycanopathy (limb-girdle), type C1	609308
Muscular Dystrophy (Duchenne)(DMD)	310200	Muscular dystrophy-dystroglycanopathy (limb-girdle), type C5	607155
Muscular Dystrophy (Oculopharangeal)(OPMD)	164300	Muscular dystrophy-dystroglycanopathy (limb-girdle), type C7	616052
Muscular dystrophy, congenital, Davignon-Chauveau type	617066	Muscular dystrophy-dystroglycanopathy, type A1 (Walker Warburg Syndrome)	236670
Muscular dystrophy, congenital, due to Integrin alpha-7 deficiency	613204	Muscular dystrophy-dystroglycanopathy, type A3 (muscle-eye-brain disease)	253280
Muscular Dystrophy, Congenital, LMNA-related, (MDCL) - for cases where there is proven evidence of mosaicism in the blood or as a result of a second affected child	613205	Muscular dystrophy-dystroglycanopathy, type A5	613153
Muscular dystrophy, congenital, megaconial type	602541		
Muscular dystrophy, congenital, with cataracts and intellectual disability	617404		
Muscular dystrophy, Limb-Girdle (LGMD) Type 1B	159001		
Muscular dystrophy, limb-girdle, autosomal recessive 17	613723		

Description	OMIM number	Description	OMIM number
Muscular dystrophy-dystroglycanopathy, types A2, A4, A6-A8 and A10-A14	613150, 253800, 613154, 614643 614830, 615041, 615181, 615249, 615287, 615350	Myasthenic syndrome, congenital, 4C	608931
Myasthenic Congenital Syndrome Type 5 (CMS5)	603034	Myasthenic syndrome, congenital, 6	254210
Myasthenic syndrome, congenital, 10	254300	Myasthenic syndrome, congenital, 7	616040
Myasthenic syndrome, congenital, 11	616326	Myasthenic syndrome, congenital, 8	615120
Myasthenic syndrome, congenital, 12	610542	Myasthenic syndrome, congenital, 9	616325
Myasthenic syndrome, congenital, 13	614750	Myoclonic Epilepsy and Ragged Red Fibres (MERRF)	545000
Myasthenic syndrome, congenital, 14	616228	Myoclonic Epilepsy of Unverricht-Lundborg Disease (ULD-EPM1)	254800
Myasthenic syndrome, congenital, 16	614198	Myoclonus Dystonia (DYT11)	159900
Myasthenic syndrome, congenital, 19	616720	Myopathy, Congenital, with Fiber-Type Disproportion (CFTD)	255310
Myasthenic syndrome, congenital, 1A, Slow-channel	601462	Myopathy, Myofibrillar 1	601419
Myasthenic syndrome, congenital, 1B, Fast-channel	608930	Myopathy, Myofibrillar 10	619040
Myasthenic syndrome, congenital, 20	617143	Myopathy, Myofibrillar 2	608810
Myasthenic syndrome, congenital, 21	617239	Myopathy, Myofibrillar 3	609200
Myasthenic syndrome, congenital, 22	616224	Myopathy, Myofibrillar 4	609452
Myasthenic syndrome, congenital, 24	618198	Myopathy, Myofibrillar 5	609524
Myasthenic syndrome, congenital, 25	618323	Myopathy, Myofibrillar 6	612954
Myasthenic syndrome, congenital, 2A, Slow-channel	616313	Myopathy, Myofibrillar 7	617114
Myasthenic syndrome, congenital, 3B, Fast-channel	616322	Myopathy, Myofibrillar 8	617258
Myasthenic syndrome, congenital, 4A, Slow-channel	605809	Myopathy, Myofibrillar 9 with early respiratory failure	603689
Myasthenic syndrome, congenital, 4B, Fast-channel	616324	Myopathy, Myofibrillar, fatal infantile hypertonic, alpha-B crystallin-related	613869

Description	OMIM number	Description	OMIM number
Myopathy, spheroid body, (due to mutations in the same gene as myopathy, myofibrillar 3 and with similar phenotype)	182920	Nephronophthisis 7, (NPHP7)	611498
Myotonia Congenita, Autosomal Dominant	160800	Nephronophthisis-like nephropathy 1	613159
Myotonia Congenita, Autosomal Recessive	255700	Nephropathic Cystinosis (CTNS)	219800
Myotonic Dystrophy	160900	Nephrotic syndrome Type 1 (NPHS1)	256300
Myotonic Dystrophy type 2	602668	Nephrotic syndrome Type 2 (NPHS2)	600995
Myotubular myopathy	310400, 300219	Netherton Syndrome	256500
Nail-Patella Syndrome (NPS)	161200	Neurodegeneration with Brain Iron Accumulation 1 (NBIA1)	234200
Nance-Horan Syndrome (NHS)	302350	Neurodegeneration with Brain Iron Accumulation 2A (NBIA2A)	256600
Nemaline Myopathy ACTA 1	161800	Neurodegeneration with Brain Iron Accumulation 2B (NBIA2B)	610217
Nemaline myopathy type 2 (NEM2)	256030	Neurodegeneration with Brain Iron Accumulation 3 (NBIA3)	606159
Nemaline Myopathy type 8	615348	Neurodegeneration with Brain Iron Accumulation 4 (NBIA4)	614298
Neonatal Inflammatory Skin and Bowel Disease 1 (NISBD1)	614328	Neurodegeneration with Brain Iron Accumulation 5 (NBIA5)	300894
Neonatal Inflammatory Skin and Bowel Disease 2 (NISBD2)	616069	Neurodegeneration with Brain Iron Accumulation 6 (NBIA6)	615643
Nephrogenic Diabetes Insipidus (NDI)	304800	Neurodevelopmental disorder with cerebral atrophy and variable facial dysmorphism (NEDCAFD)	619244
Nephronophthisis 1, (NPHP1)	256100	Neurodevelopmental Disorder with Progressive Microcephaly Spasticity and Brain Anomalies (NDMSBA)	617527
Nephronophthisis 11, (NPHP11)	613550	Neurofibromatosis type 1 (NF1)	162200
Nephronophthisis 12, (NPHP12)	613820	Neurofibromatosis Type 2 (NF2)	101000
Nephronophthisis 13, (NPHP13)	614377	Neurogenic muscle weakness, Ataxia, Retinitis Pigmentosa (NARP)	551500
Nephronophthisis 14, (NPHP14)	614844	Neuronal Ceroid Lipofuscinosis Type 3 (Batten disease) (CLN3)	204200
Nephronophthisis 15, (NPHP15)	614845	Neuronopathy Distal Hereditary Motor, Type 2C (HMN2C)	613376
Nephronophthisis 16, (NPHP16)	615382	Neuronopathy Distal Hereditary Motor, Type 2D (HMN2D)	615575
Nephronophthisis 18, (NPHP 18)	615862	Neuronopathy Distal Hereditary Motor, Type 5A (HMN5A)	600794
Nephronophthisis 19, (NPHP 19)	616217	Neuronopathy Distal Hereditary Motor, Type 5B (HMN5B)	614751
Nephronophthisis 2, (NPHP2)	602088	Neuronopathy Distal Hereditary Motor, Type 5C (HMN5C)	619112
Nephronophthisis 20, (NPHP 20)	617271	Neuronopathy Distal Hereditary Motor, Type 7A (HMN7A)	158580
Nephronophthisis 3, (NPHP3)	604387		
Nephronophthisis 4, (NPHP4)	606966		

Description	OMIM number	Description	OMIM number
Neuronopathy Distal Hereditary Motor, Type 7B (HMN7B)	607641	Optic Atrophy 1 (OPA1)	165500
Neuronopathy Distal Hereditary Motor, Type IX (HMN9)	617721	Ornithine transcarbamylase deficiency (OTD)	311250
Neuronopathy, distal hereditary motor, type VIII (HMN8)	600175	Orofaciodigital Syndrome 1 (OFD1)	311200
Neuropathy, distal hereditary motor, type IIA (HMN2A)	158590	Orofaciodigital Syndrome 7 (OFD7)	608518
Niemann-Pick Disease Type A	257200	Osteogenesis Imperfecta Type I (OI1)	166200
Niemann-Pick disease Type C1 and D	257220	Osteogenesis Imperfecta Type II	166210
non-Herlitz Junctional Epidermolysis Bullosa	226650	Osteogenesis Imperfecta Type III (OI3)	259420
Non-Ketotic Hyperglycinaemia (NKH)/ Glycine Encephalopathy (GCE)	605899	Osteogenesis Imperfecta Type IV , Type V & Type VI	166220, 610967, 613982
Noonan Syndrome	163950	Osteogenesis Imperfecta type IX (OI type IX)	259440
Noonan Syndrome Type 10	616564	Osteogenesis Imperfecta type VII (OI type VII)	610682
Noonan Syndrome Type 2	605275	Osteogenesis Imperfecta Type VIII (OI8)	610915
Noonan Syndrome Type 3	609942	Osteogenesis Imperfecta type X (OI type X)	613848
Noonan Syndrome Type 4	610733	Osteogenesis Imperfecta type XI (OI type XI)	610968
Noonan Syndrome Type 5	611553	Osteogenesis Imperfecta type XII (OI type XII)	613849
Noonan Syndrome Type 6	613224	Osteogenesis Imperfecta type XIII (OI type XIII)	614856
Noonan Syndrome Type 7	613706	Osteogenesis Imperfecta type XIV (OI type XIV)	615066
Noonan Syndrome Type 8	615355	Osteogenesis Imperfecta type XV (OI type XV)	615220
Noonan Syndrome Type 9	616559	Osteogenesis Imperfecta, Type XIX (OI19)	301014
Norrie Disease	310600	Osteopetrosis with Renal Tubular Acidosis (OPTB3)	259730
Oculocutaneous Albinism Type 1A (OCA1A)	203100	Osteopetrosis, Autosomal Recessive 5 (OPTB5) and Osteopetrosis, Infantile Malignant 3	259720
Oculocutaneous Albinism Type 1B (OCA1B)	606952	Ostheopathia Striata with Cranial Sclerosis (OSCS)	300373
Oculocutaneous albinism type 2	203200	Otodental Dysplasia	166750
Oculodentodigital Dysplasia (ODDD)	164200	Otopalatodigital syndrome Type 2 (OPD2)	304120
Oculodentodigital Dysplasia (ODDD)	257850	Otopalatodigital type 1	311300
Olmsted Syndrome, X-Linked (OLMSX)	300918	Pachyonychia Congenita Type 1	167200
Omenn Syndrome	603554	Pachyonychia Congenita Type 2	167210

Description	OMIM number	Description	OMIM number
Pachyonychia Congenita Type 3	615726	Phenylketonuria (PKU)	261600
Pachyonychia Congenita Type 4	615728	Photosensitive Trichothiodystrophy 1 (TTD1)	601675
Palmoplantar keratoderma, epidermolytic (EPPK)	144200	Pituitary Adenoma Type 1	102200
Palmoplantar keratoderma, non-epidermolytic (NEPPK)	600962	Pituitary Adenoma Type 2	300943
Palmoplantar Keratoderma, Nonepidermolytic, Focal or Diffuse	615735	Pituitary Adenoma Type 5	617540
Panhypopituitarism, X-linked; PHPX	312000	Pleuropulmonary Blastoma Familial Tumor Predisposition Syndrome	601200
Paragangliomas 4 (PGL4)	115310	Polycystic kidney disease (PKD4)	263200
Paramyotonia Congenita (PMC)	168300	Polycystic Kidney Disease- type 2 (PKD2)	613095
Paramyotonia Congenita of von Eulenburg	168300	Polycystic Kidney Disease-type 3 (PKD3)	600666
Parkinson's disease 8	607060	Polycystic Kidney Disease-type 5 (PKD5)	617610
Parkinson’s disease 1	168601	Polycystic Kidney Disease-type 6 (PKD6)	618061
Parkinson’s disease 4	605543	Polymicrogyria in association with homozygous/compound heterozygous ATP1A2 variants (autosomal recessive)	*182340
Paroxysmal extreme pain disorder (PEPD)	167400	Pontocerebellar Hypoplasia type 1a, type 2a, type 2b, type 2c, type 2d , type 3, type 4, type 6	607596, 277470, 612389, 612390, 613811, 608027, 225753, 611523
Partial androgen insensitivity syndrome due to defects in the androgen receptor gene	312300	Pontocerebellar Hypoplasia type 1B (PCH1B)	614678
Partial Lipodystrophy, Familial Type 2 (FPLD2)	151660	Pontocerebellar hypoplasia, hypotonia, and respiratory insufficiency syndrome, neonatal lethal	618810
Partner and Localizer of BRCA2 (PALB2)	610355	Popliteal Pterigum Syndrome (PPS)	119500
Pelizaeus Merzbacher Disease	312080	Porencephaly 1	175780
Pendred Syndrome (PDS)	274600	Prader Willi Syndrome (PWS)	176270
Periodic Fever, Familial, Autosomal Dominant (FPF),	142680	Primary Ciliary Dyskinesia Type 1 (CILD1	244400
Peroxisome Biogenesis Disorders (PBD) (Zellweger Syndrome Spectrum (ZSS))		Primary Ciliary Dyskinesia Type 10 (CILD10)	612518
Pettigrew syndrome	304340	Primary Ciliary Dyskinesia Type 11 (CILD11)	612649
Peutz-Jeghers Syndrome (PJS)	175200		
Pfeiffer syndrome, OMIM	101600		

Description	OMIM number	Description	OMIM number
Primary Ciliary Dyskinesia Type 12 (CILD12)	612650	Primary Ciliary Dyskinesia Type 34 (CILD34)	617091
Primary Ciliary Dyskinesia Type 13 (CILD13)	613193	Primary Ciliary Dyskinesia Type 35 (CILD35)	617092
Primary Ciliary Dyskinesia Type 14 (CILD14)	613807	Primary Ciliary Dyskinesia Type 37 (CILD37)	617577
Primary Ciliary Dyskinesia Type 15 (CILD15)	613808	Primary Ciliary Dyskinesia Type 5 (CILD5)	608647
Primary Ciliary Dyskinesia Type 15 (CILD15)	613808	Primary Ciliary Dyskinesia Type 6 (CILD6)	610852
Primary Ciliary Dyskinesia Type 16 (CILD16)	614017	Primary Ciliary Dyskinesia Type 7 (CILD7)	611884
Primary Ciliary Dyskinesia Type 16 (CILD16)	614017	Primary Ciliary Dyskinesia Type 9 (CILD9)	612444
Primary Ciliary Dyskinesia Type 17 (CILD17)	614679	Primary Microcephaly 1 (MCPH1)	251200
Primary Ciliary Dyskinesia Type 18 (CILD18)	614874	Primary Microcephaly 10 (MCPH10)	615095
Primary Ciliary Dyskinesia Type 19 (CILD19)	614935	Primary Microcephaly 13 (MCPH13)	616051
Primary Ciliary Dyskinesia Type 2 (CILD2)	606763	Primary Microcephaly 14 (MCPH14)	616402
Primary Ciliary Dyskinesia Type 20 (CILD20)	615067	Primary Microcephaly 15 (MCPH15)	616486
Primary Ciliary Dyskinesia Type 21 (CILD21)	615294	Primary Microcephaly 16 (MCPH16)	616681
Primary Ciliary Dyskinesia Type 22 (CILD22)	615444	Primary Microcephaly 17 (MCPH17)	617090
Primary Ciliary Dyskinesia Type 23 (CILD23)	615451	Primary Microcephaly 19 (MCPH19)	617800
Primary Ciliary Dyskinesia Type 24 (CILD24)	615481	Primary Microcephaly 2 (MCPH2)	604317
Primary Ciliary Dyskinesia Type 25 (CILD25)	615482	Primary Microcephaly 20 (MCPH 20)	617914
Primary Ciliary Dyskinesia Type 26 (CILD26)	615500	Primary Microcephaly 21 (MCPH 21)	617983
Primary Ciliary Dyskinesia Type 27 (CILD27)	615504	Primary Microcephaly 22 (MCPH 22)	617984
Primary Ciliary Dyskinesia Type 28 (CILD28)	615505	Primary Microcephaly 25 (MCPH25)	618351
Primary Ciliary Dyskinesia Type 29 (CILD29)	615872	Primary Microcephaly 3 (MCPH3)	604804
Primary Ciliary Dyskinesia Type 3 (CILD3)	608644	Primary Microcephaly 4 (MCPH4)	604321
Primary Ciliary Dyskinesia Type 30 (CILD30)	616037	Primary Microcephaly 5 (MCPH5)	608716
Primary Ciliary Dyskinesia Type 32 (CILD32)	616481	Primary Microcephaly 6 (MCPH6)	608393
Primary Ciliary Dyskinesia Type 33 (CILD33)	616726	Primary Microcephaly 7 (MCPH7)	612703

Description	OMIM number	Description	OMIM number
Primary Microcephaly 8 (MCPH8)	614673	Renal cell carcinoma, papillary, 1 (RCCP1)	605074
Primary Microcephaly 9 (MCPH9)	614852	Renal Coloboma Syndrome	120330
Prion disease with protracted course	606688	Renal Cysts and Diabetes (RCAD)	137920
Progressive External Opthalmoplegia with Mitochondrial DNA Deletions, Autosomal Dominant 3 (PEOA3)	609286	Retinal macular dystrophy 2	608051
Progressive Familial Intrahepatic Cholestasis Type 1 (PFIC1)	211600	Retinitis Pigmentosa (autosomal dominant)	180100
Prolidase Deficiency	170100	Retinitis Pigmentosa (RP3) (x-linked)	300029
Propionic Acidemia	606054	Retinitis Pigmentosa (x-linked)	300455
Pseudo-TORCH syndrome-type 1	251290	Retinitis pigmentosa 2 (RP2)	312600
Pseudo-TORCH syndrome-type 2	617397	Retinitis Pigmentosa Type 11 (RP11)	600138
Pseudoachondroplasia	177170	Retinitis Pigmentosa type 7 (RP7)	608133
Pseudohypoparathyroidism (PHP1a)	103580	Retinoblastoma (RB1)	180200
Pseudovaginal Perineoscrotal Hypospadias due to 5-Alpha-Reductase Deficiency (insofar as that condition affects males, with simultaneous sex determination)	264600	Rett Syndrome (RTT) and Neonatal Encephalopathy	312750, 300673
Pyogenic Arthritis, Pyoderma Gangrenosum and Acne Syndrome (PAPA)	604416	Rhabdomyosarcoma, embryonal 2	180295
Pyrodoxine-dependent seizures (EPD)	266100	Rhesus disease/ Haemolytic Disease of the Newborn (HDN)	
Pyruvate dehydrogenase E1-alpha deficiency X-linked	312170	Rhizomelic Chondrodysplasia Punctata (RCDP1) Type 1	215100
Pyruvate Dehydrogenase E1-beta Deficiency	614111	Rhizomelic Chondrodysplasia Punctata (RCDP2) Type 2	222765
Pyruvate Dehydrogenase, Alpha-1 (PDHA1)	312170	Rhizomelic Chondrodysplasia Punctata (RCDP3) Type 3	600121
Radioulnar synostosis with amegakaryocytic thrombocytopenia type 1 (RUSAT1)	605432	Rhizomelic Chondrodysplasia Punctata (RCDP5) Type 5	616716
Radioulnar synostosis with amegakaryocytic thrombocytopenia type 2 (RUSAT2)	616738	Right Atrial Isomerism (RAI)	208530
Rapp-Hodgkin Syndrome (RHS)	129400	Rigid spine muscular dystrophy	602771
Recurrent Digynic Triploidy		Robinow Syndrome Autosomal Dominant-Type 1 (DRS1)	180700
Recurrent hydatidiform mole (HYDM1)	231090	Robinow Syndrome Autosomal Dominant-Type 2 (DRS2)	616331
Recurrent infections with encephalopathy, hepatic dysfunction and cardiovascular malformations (FADD deficiency)	613759	Robinow Syndrome Autosomal Dominant-Type 3 (DRS3)	616894

Description	OMIM number	Description	OMIM number
Robinow Syndrome Autosomal Recessive-Type 1 (RRS1)	268310	Senior-Loken Syndrome type 7 (SLSN7)	613615
Robinow Syndrome Autosomal Recessive-Type 2 (RRS2)	618529	Senior-Loken Syndrome type 8 (SLSN8)	616307
Rothmund-Thomson Syndrome (RTS)	268400	Senior-Loken Syndrome type 9 (SLSN9)	616629
Saethre-Chotzen Syndrome (SCS)	101400	Severe / Profound Global Developmental Delay and Epilepsy (GRM7 gene)	604101
Salih myopathy	611705	Severe Combined Immune Deficiency (x-linked) (SCIDX1)	300400
Salla Disease	604369	Severe Combined Immunodeficiency (SCID)	601457
Sandhoff Disease	268800	Severe Combined Immunodeficiency (SCID) (Adenosine Deaminase (ADA) deficient)	102700
Sanjad Sakati Syndrome (SLSN6)	241410	Severe Combined Immunodeficiency – autosomal recessive	600802
Scapuloperoneal spinal muscular atrophy (SPSMA)	181405	Short-Rib Thoracic Dysplasia, types 2 - 11, 13 and 14	611263, 613091, 613819, 614376, 263520, 614091, 615503, 266920, 615630, 615633, 616300, and 616546
Schaaf-Yang Syndrome	615547	Shwachman-Diamond syndrome (SDS)	260400
Schwannomatosis type 1	162091	Sialic Acid Storage Disorder (ISSD)	269920
Schwannomatosis type 2	615670	Sickle Cell Anaemia*	603903
Seizures, Cortical Blindness, Microcephaly Syndrome (SCBMS)	616632	Simpson Golabi Behmel Syndrome Type 1	312870 (to detect affected males)
Sengers Syndrome	212350	Simpson-Golabi-Behmel Syndrome Type 2	300209
Senior-Loken Syndrome type 1 (SLSN1)	266900	Sjogren Larsson Syndrome (SLS)	270200
Senior-Loken Syndrome type 4 (SLSN4)	606996	Small-fibre neuropathy (SFN)	133020
Senior-Loken Syndrome type 5 (SLSN5)	609254	Smith Lemli Opitz Syndrome (SLOS)	270400
Senior-Loken Syndrome type 6 (SLSN6)	610189	SOPH Syndrome (Short Stature, Optic Nerve Atrophy, Pelger-Huet anomaly)	614800

Description	OMIM number	Description	OMIM number
Sotos syndrome 1	117550	Spinocerebellar ataxia 34 (SCA34)	133190
Spastic Ataxia 1, Autosomal Dominant (SPAX1)	108600	Spinocerebellar ataxia 35 (SCA35)	613908
Spastic Ataxia 2, Autosomal Recessive (SPAX2)	611302	Spinocerebellar ataxia 36 (SCA36)	614153
Spastic Ataxia 3, Autosomal Recessive (SPAX3)	611390	Spinocerebellar ataxia 37 (SCA37)	615945
Spastic Ataxia 5, Autosomal Recessive (SPAX5)	614487	Spinocerebellar ataxia 38 (SCA38)	615957
Spastic Ataxia 8, Autosomal Recessive with Hypo-Myelinating Leukodystrophy (SPAX8)	617560	Spinocerebellar ataxia 42 (SCA42)	616795
Spastic Ataxia, Charlevoix-Saguenay (SACS)	270550	Spinocerebellar ataxia 44 (SCA44)	617691
Spastic paraplegia		Spinocerebellar ataxia 47 (SCA47)	617931
Spinal and Bulbar Muscular Atrophy X-linked (Kennedy disease) (in affected male embryos)	313200	Spinocerebellar ataxia 5 (SCA5)	600224
Spinal Muscular Atrophy 1 (SMA1)	253300	Spinocerebellar ataxia 8 (SCA8)	608768
Spinal Muscular Atrophy and Respiratory Distress (SMARD1)	604320	Spinocerebellar Ataxia Autosomal Recesive 20, SCAR20 (SNX14-related cerebellar hypoplasia)	616354
Spinal muscular atrophy type 2	253550	Spinocerebellar Ataxia Type 1 (SCA1)	164400
Spinal muscular atrophy type 3	253400	Spinocerebellar ataxia type 14	605361
Spinocerebella rataxia 21 (SCA21)	607454	Spinocerebellar Ataxia Type 2 (SCA2)	183090
Spinocerebellar ataxia 10 (SCA10)	603516	Spinocerebellar Ataxia Type 3 (SCA 3) (Machado Joseph Disease)	109150
Spinocerebellar ataxia 11 (SCA11)	604432	Spinocerebellar Ataxia Type 6 (SCA6)	183086
Spinocerebellar ataxia 12 (SCA12)	604326	Split hand/foot malformation 3 (SHFM3)	246560
Spinocerebellar ataxia 13 (SCA13)	605259	Split hand/foot malformation with long bone deficiency type 3 (SHFLD3)	612576
Spinocerebellar ataxia 15 (SCA15)	606658	Spondylo-epiphyseal dysplasia, Maroteaux type	184095
Spinocerebellar ataxia 17 (SCA17)	607136	Spondyloepimetaphyseal dysplasia, Strudwick	184250
Spinocerebellar ataxia 19 (SCA19)	607346	Spondyloepiphyseal Dysplasia Congenita	183900
Spinocerebellar ataxia 20 (SCA20)	608687	Spondyloepiphyseal dysplasia tarda, X-linked (SEDT)	313400
Spinocerebellar ataxia 23 (SCA23)	610245	Spondyloepiphyseal Dysplasia with Congenital Joint Dislocations (SEDCJD)	143095
Spinocerebellar ataxia 27 (SCA27)	609307	Spondylometaepiphyseal Dysplasia Short Limb Hand type (SMED-SL)	271665
Spinocerebellar ataxia 28 (SCA28)	610246	Spondylometaphyseal dysplasia, Kozlowski type (SMDK)	184252
Spinocerebellar ataxia 29 (SCA29)	117360	Stargardt disease type 1	248200
Spinocerebellar ataxia 31 (SCA31)	117210		

Description	OMIM number	Description	OMIM number
Stickler Syndrome Type I, II, III and IV	108300, 609508, 604841, 184840, 614134	Transcobalamin II Deficiency	275350
Stuve-Wiedemann Syndrome (Schwartz-Jampel Type 2 syndrome)	601559	Treacher Collins Syndrome 1 (TCS1)	154500
Succinic Semialdehyde Dehydrogenase Deficiency (SSADHD)	271980	Treacher Collins Syndrome Type 2 (TCS2)	613717
Sudden Cardiac Failure, Alcohol Induced (SCFAI)	617223	Trichorhinophalangeal syndrome type 1	190350
Sudden Cardiac Failure, Infantile (SCFI)	617222	Tuberous Sclerosis (TSC1 and TSC2)	191100, 613254
Surfactant Metabolism Dysfunction, Pulmonary Type 1 (SMDP1)	265120	Turner syndrome (Mosaic)	
Surfactant Metabolism Dysfunction, Pulmonary Type 3 (SMDP3)	610921	Tyrosinaemia Type 1	276700
Surfactant Metabolism Dysfunction, Pulmonary, Type 2 (SMDP2)	610913	Tyrosine Hydroxylase Deficiency	605407
Susceptibility to breast cancer due to a mutation in the c.7271T>G Ataxia-Telangiectasia Mutated (ATM) Gene	*607585	UBE2A - Intellectual Disability type Nascimento - X linked	300860
Syndromic Microphthalmia 1 (MCOPS1) (Lenz syndrome)	309800	Ullrich Congenital Muscular Dystrophy 1 (UCMD1)	254090
Syndromic Microphthalmia 12 (MCOPS12)	615524	Usher syndrome type 1 (including subtypes 1B, 1C, 1D, 1F, 1G, 1J)	276900 276904 601067 602083 606943 614869
Tay Sachs Disease (infantile onset) (TSD)	272800	Usher syndrome type 2 (including subtypes 2A, 2C and 2D)	276901, 605472, 611383
Temtamy syndrome (TEMTYS)	218340	Van der Woude syndrome Type 1	119300
Thiamine Metabolism Dysfunction Syndrome 2	607196	Vasculopathy, Retinal, with Cerebral Leukodystrophy (RVCL)	192315
Thiamine Metabolism Dysfunction Syndrome 3	607196	Vici syndrome (VICIS)	242840
Thiamine Metabolism Dysfunction Syndrome 5	614458	Von Hippel Lindau syndrome (VHL)	193300
Thiamine-responsive Megaloblastic Anaemia	249270	Waardenburg Syndrome Type I (WS1)	193500
Thrombocytopenia Absent Radius (TAR) Syndrome	274000	Waardenburg Syndrome Type IIa (WS2A)	193510
Timothy Syndrome (TS)	601005	Waardenburg Syndrome Type IId (WS2D)	608890
Townes-Brocks Syndrome	107480	Waardenburg Syndrome Type IIe (WS2E)	611584
TPRN-associated autosomal recessive non-syndromic deafness (DFNB79)	613307	Waardenburg Syndrome Type III (WS3)	148820

Description	OMIM number	Description	OMIM number
Waardenburg Syndrome Type IVa (WS4A)	277580	X-linked Chronic Granulomatous Disease (CGDX)	306400
Waardenburg Syndrome Type IVb (WS4B)	613265	X-linked Ectodermal dysplasia 1 (Hypohidrotic)	305100
Waardenburg Syndrome Type IVc (WS4C)	613266	X-linked heterotaxy 1 (HTX1) - ZIC3 associated congenital heart defects and heterotaxy	306955
Werner Syndrome (WRN)	277700	X-linked Hydrocephalus (HSAS)	307000
Wiscott-Aldrich Syndrome (WAS)*	301000	X-linked lissencephaly	300067
Wolcott-Rallison Syndrome	226980	X-Linked Lymphoproliferative Disease Type 2 (XLP2) (Male Embryos Only)	300365
Wolfram-like Syndrome (WLS)	614296	X-linked Ocular Albinism	300500
Wolman's Disease (Acid Lipase Deficiency)	278000	X-linked Opitz GBBB syndrome Type 1	300000
Woodhouse-Sakati Syndrome	241080	X-Linked Reducing Body Myopathy - severe infantile/early childhood onset	300717
X Linked Periventricular Heterotopia (PVNH1)	300049	X-linked Retinoschisis (RS1)	312700
X-linked Adrenal Hypoplasia Congenita (XL-AHC)	300200	X-Linked Thrombocytopenia (XLT)	313900
X-linked Cardiac Valvular Dysplasia	314400	XMEN syndrome (X Linked magnesium defect, EBV, neoplasia)	300853

Other Conditions Relevant to the Health of the Person	
With regard to Birth Mother	**OMIM Number**
Maternal substance abuse	606581
Hx of maternal psychosis esp peripartum psychosis	
Hx of preterm birth	
Hx of pre-eclampsia or eclampsia	614595
HX of recurrent miscarriage	614389
HX of pre-term birth (and gestation if known)	
Hypertension – essential or gestational	
Diabetes – Type 1 . 2 or gestational	125853
With regard to other Genetic Relatives	**OMIM Number**
Bleeding or Coagulation Disorders	
Enduring mental health disorders	
HX of premature ovarian failure relevant	