



PO Box 969 Penrith NSW 2751
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 ABN: 99 117 585 976
 Email: info@idfa.org.au
 Web: www.idfa.org.au
 DGR1 & TCC

NSW CFN 18607
 VIC CFN 9477
 QLD CFN 1544
 ACT Lic No L9000564
 TAS F1A-164
 SA CCP 3319



IDFA Privacy and Confidentiality Policy
 Governance
 Privacy and Confidentiality Code of Conduct

Policy number	IDFA_Pol&Pro_Gov_Privacy Policy	Version	1
Drafted by	C Jeffery	Approved by	28/12/2018
Responsible person	Board, Staff, volunteers and members	Board on	
IDFA Board Chair	L ALEXANDER	Scheduled	03/10/2021
		review date	

The IDFA will only collect, store, use, disclose and destroy your personal information in accordance with the *Privacy Act 1988*.

Schedule 1 to the *Privacy Act 1988* contains the Australian Privacy Principles which regulate the way in which organisations and government departments can collect and use personal information.

The IDFA's Privacy Policy sets out the way in which the IDFA complies with these principles. The full policy can be downloaded below, or you can click on the links below to find out more information.

IDFA Privacy Policy

The IDFA's privacy policy can be read in full and downloaded below.

www.idfa.org.au

When you view our website or log in to the IDFA Charity Portal, a record of your visit is logged for statistical purposes. This record includes the following information which is provided by your browser:

- the user's server address
- the user's top level domain name (for example .com, .gov, .au, .uk etc)
- the date and time of visit to the site
- the pages accessed and documents downloaded
- the previous site visited
- the type of browser used.

This information is used for statistical purposes, as well as helping us to maintain our server and to improve our services. This information will not be disclosed to any other government agency, organisation or individual unless we are required by law to do so.

Email addresses

If you subscribe to our email updates, we will need to collect your email address and only use your address for the purpose for which you have provided it. Your email address will not be disclosed to any other government agency, organisation or individual.

IDFA Charity Portal (not in operation as yet)

Some fields in the portal require you to provide additional personal information than that which is covered by this privacy statement (for example, when updating responsible person details). Additional information in relation to your privacy will be provided on the portal.

Corporate Policy: IDFA Privacy Policy

This Corporate Policy is issued under the authority of the IDFA Board.
 About this Privacy Policy



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This policy sets out how the IDFA will comply with the Australian Privacy Principles (APPs) contained in Schedule 1 to the Privacy Act 1988. In particular, this policy demonstrates the IDFA's compliance with APP 1 - Open and transparent management of personal information. The APPs are contained in Schedule 1 to the Privacy Act 1988 and are legally binding on the IDFA. The APPs regulate the way in which organisations and government agencies can collect, store, use and disclose personal information and how you can access and correct that information. Detailed information on the APPs can be found on the Office of the Australian Information Commissioner's (OAIC) website www.oaic.gov.au.

Background

IDFA is a non-profit organisation and a registered charity. IDFA is a member of IPOPI (the International Patient Organisation for Primary Immune Deficiencies). IDFA has the support of leading Immunology health professionals both in Australia, New Zealand and Internationally. The Foundation's primary aim is to raise awareness of primary and secondary immune deficiencies within both the general and medical communities.

What is personal information?

Personal information is information or an opinion about an individual:

whether or not the information or opinion is true or not; and

whether the information or opinion is recorded in a material form or not.

The APPs apply only to information about individuals. The APPs do not cover information about charitable entities.

If the IDFA does not collect personal information about you, the Privacy Act will not apply.

Who should read this Privacy Policy

You should read this Privacy Policy if you are:

- An individual who is a responsible entity for the IDFA (i.e. a director of a company or a trustee of a trust that is a registered charity).
- A contact person for the IDFA.
- An agent for the IDFA.
- An individual whose personal information may be given to or held by the IDFA.
- A contractor, consultant or supplier or vendor of goods or services to the IDFA.
- A person seeking employment with the IDFA; or
- A person employed by the IDFA.

Our personal information handling practices

Collection of personal information

The IDFA will always endeavour to collect any required personal information from you directly.

Common ways we collect and use personal information

At the registration stage

When applying for membership, we will ask for personal information about the patient and their responsible person/family members.

If the responsible person wants to contact the IDFA to discuss confidential, we need to have enough information on our record to conduct a Proof of Identity (POI) check. Your information will be saved on the IDFA database.

If the responsible person is not the same person who is completing the registration form, we will also ask for personal information belonging to the person who is completing the form on behalf of the patient.

If the online registration form is started but not submitted to the IDFA, the applicant will be prompted to complete the form. If the form remains pending after eight months, it will be deleted from the system as part of the IDFA's commitment to ensuring that personal information we collect is accurate, up to date and complete.



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Personal information

Completing forms

Each time you complete a form with IDFA, we may ask for your personal information. We ask for this information to assist IDFA in research and grant purposes. All information is de-identified.

We may also request the details of an alternative contact if you would like us to contact someone else should we have any follow up questions with regard to the particular form or report. Providing this personal information is voluntary. However it enables us to conduct a POI check so that we can discuss the content of the particular form with you.

If any online form is started but not submitted to the IDFA, the applicant will be prompted to complete the form. If the form remains pending after eight months, it will be deleted from the system as part of the IDFA's commitment to ensuring that personal information we collect is accurate, up to date and complete.

Advice Services

If you telephone us to discuss your health details, we will need to conduct a proof of identity 'POI' check to ensure that you are a person authorised to discuss confidential matters of IDFA. When conducting POI we will ask you a number of questions (generally three) that relate to information we hold about you on our system. We ask you this information so that we can verify your identity.

Information from other agencies and departments

We will collect your personal information from other agencies and government departments to whom you have reported only if you give us permission to do so.

Research network

The IDFA database is used for research and information purposes to gather facts about immune deficiencies.

The IDFA manages a mailing list for network members. Persons who wish to be added to this list provide their details voluntarily. When the IDFA adds a person to the list, their name, workplace, email address and phone number are collected.

Education sessions

The IDFA conducts face to face education and training sessions. Participant details are collected (voluntarily) to facilitate registration for these sessions.

Employee information

When you commence employment with the IDFA, the IDFA will collect the information it needs from you for human resource purposes. This information is stored in an electronic database called MYOB. This information is kept confidential and only a select number of IDFA human resource officers have access to the MYOB system.

This information is used for employment related purposes only.

If employees or managers want access to information contained in the database, they must contact the CEO of IDFA.

Use and disclosure of personal information

When we collect personal information, we will notify you of the purpose for which we are collecting it. Generally, we will only use or disclose your personal information for the very purpose for which it was collected.

We will only use and disclose your information where the use or disclosure is lawful.

The most common ways we collect personal information and the reasons we collect it are explained in detailed above in the section headed "Common ways we collect and use personal information."

Accidental or unauthorised use or disclosure

The IDFA will take seriously and deal promptly with any accidental or unauthorised disclosure of personal information.



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All IDFA employees are made aware of their obligations to handle personal information in accordance with the Privacy Act.

Our practices and procedures are regularly reviewed to ensure ongoing compliance with the Privacy Act.

Where an accidental or unauthorised use or disclosure occurs, the IDFA will act quickly to rectify and remedy the situation.

External service providers contracted by the IDFA are bound contractually to comply with the requirements of the Privacy Act.

Potential accidental or unauthorised use or disclosure of information, including personal information, is also covered by the following:

Where an employee discloses personal information that is also protected information unlawfully, they will be subject to penalties including, in the most serious cases, up to two years imprisonment.

All IDFA employees are covered by the Public Service Act 1999, the Public Service Regulations 1999 and the Australian Public Service (APS) Values and Code of Conduct. If employees disclose official information without authority they may face disciplinary sanctions including, in the most serious cases, termination of employment.

Current and former employees and service providers are generally covered by the Crimes Act 1914 which provides for criminal penalties for unauthorised disclosure of official information.

The Criminal Code Act 1995 provides for similar penalties if former employees dishonestly use official information gained during their employment to benefit themselves or others or to cause harm to another person.

Storage and data security

We take reasonable steps to protect the personal information we hold from misuse, interference, loss, unauthorised access, modification or disclosure. We do this by ensuring that:

Personal information collected by the IDFA is collected and stored in accordance with Australian Government security policy. All paper files are secured in locked cabinets, Australian Government approved security containers or Secure Rooms with restricted access.

Information that has been stored electronically can only be accessed by IDFA officers.

Our internal network and databases are protected using firewall, intrusion detection and other technologies.

The IDFA's premises are under 24 hour surveillance and access is via alarm code and key only, with all access and attempted access logged electronically.

All IDFA employees and service providers are made aware of their obligations under the Privacy Act during the induction stage of their employment. Ongoing training is provided to ensure that we adhere to our established security practices.

Records management

All Commonwealth agencies, and the IDFA, are bound by the Archives Act 1983. This means that all our records management policies, including storage and destruction of information, are in accordance with the Archives Act 1983, Records Authorities and General Disposal Authorities.

Other Acts which impact on our records management policies are:

- The Australian Charities and Not-for-profits Act 2012
- The Freedom of Information Act 1982
- The Australian Information Commissioner Act 2010
- The Privacy Act 1988
- The Electronic Transactions Act 1999
- The Financial Management and Accountability Act 1997



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Access to your personal information

You have a right under Australian Privacy Principle 12 to access the personal information we hold about you.

There is no charge for making a request.

You can make a request for access to the personal information we hold about you by contacting us at info@idfa.org.au, phone 1800 100 198 or PO Box 969 Penrith NSW 2751.

You will need to include the following details in your request:

That you are making a request for access to the personal information we hold about you under the Privacy Act.

Your full name, date of birth and contact details (phone number, address or email address that we will have on our systems). We ask for this information so that we can verify your identity.

An address (email or postal address) that you would like the information you have requested forwarded to.

A contact phone number so that we can speak with you if we need any further details regarding your request.

Any relevant details regarding the information you are requesting.

We will respond to your request within 30 days.

Note that the IDFA may refuse to give access to personal information or refuse to give the information in the manner requested where we are required or authorised to refuse access under the Freedom of Information Act 1982 or another Act of the Commonwealth or a Norfolk Island enactment that provides for access by persons to documents.

If we make a decision to refuse to give access or refuse to give access in the manner you have requested we will send a written notice to the address you have provided to us, outlining our reasons for refusal (except to the extent that having regard to the grounds for the refusal, it would be unreasonable to do so).

We will also let you know the mechanisms available to you to complain about the refusal.

You may also request access to information we hold about you under the Freedom of Information Act 1982.

Correction of personal information

You can make a request for us to correct personal information we hold about you where you believe that information is out of date, inaccurate, incomplete, irrelevant or misleading.

There is no charge for making the request.

You can make a correction to the personal information we hold about you by changing your details via IDFA portal at: <https://charity.IDFA.gov.au>. You may also [contact us](#).

Anonymity and use of a pseudonym

In some instances, you will have the right to not identify yourself or to use a pseudonym when dealing with the IDFA.

However, in some instances it will be impracticable for the IDFA to deal with you without identifying you. Alternatively, we may be required by law to deal with identified individuals.

However, an example where you may be entitled to remain anonymous or to use a pseudonym is where you would like to make a complaint about a charity or where you would like to provide the IDFA with feedback.

The right to anonymity and the use of a pseudonym will be decided on a case by case basis in accordance with Australian Privacy Principle 2.

Data quality

The IDFA is committed to monitoring, maintaining and improving the quality of our products and services.

In the event that become aware that data we hold is inaccurate, out of date, misleading or incorrect, we will take proactive steps to correct the information.



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Email communication

We will use email to correspond with you where you have indicated that this is your preferred mode of communication.

There are risks when transmitting information over the internet, including via email. We will consider these risks before we make an informed decision based on all the circumstances to correspond with you via email.

You should also be aware of these risks when sending personal information to us via email. If this is a concern to you, then you should use other methods of communication with the IDFA such as post, fax or phone.

Complaints

How to make a complaint

If you think the IDFA has breached your privacy rights, you may contact us by:

Phone: 1800 100 198 weekdays 9:00 am to 4:00 pm AEST

Email: info@idfa.org.au

Write to:

CEO

The Immune Deficiencies Foundation Australia

PO Box 969 Penrith NSW 2751

Please mark your feedback "Attention: Privacy Contact Officer" when sending it via any of the above methods.

The IDFA's complaint handling procedure

We will respond to your complaint within a reasonable time. This will usually be within 30 days. If for any reason we need additional time to provide a considered response to your complaint, we will contact you to explain the delay and let you know an expected timeframe.

How to make a complaint to the Federal Privacy Commissioner

If you are not happy with the way the IDFA handles your privacy complaint, you may contact the Federal Privacy Commissioner.

You may also make a complaint directly to the Privacy Commissioner before contacting us.

However, the Privacy Commissioner will generally recommend that you try to resolve your complaint by contacting us in the first instance.

You can contact the Privacy Commissioner by:

Phone: 1300 363 992

Email: privacy@privacy.gov.au

Write to:

The Privacy Commissioner

The Office of the Australian Information Commissioner

GPO Box 5218

Sydney NSW 2001

How to contact us

Most updates or changes to your personal information can be done via IDFA portal <https://idfa.org.au/>

If you have any questions about changes to your personal information, this Privacy Policy or you wish to make a complaint about a breach of your privacy you may contact IDFA Advice Services

Phone: 1800 100 198 weekdays 9:00 am to 4:00 pm AEST

Email: info@idfa.org.au

Write to:

CEO

The Immune Deficiencies Foundation Australia

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Relevant documents:

- IDFA Non-disclosure Agreement
- IDFA Privacy Principles
- National Privacy Principles
- The Australian Charities and Not-for-profits Act 2012
- The Freedom of Information Act 1982
- The Australian Information Commissioner Act 2010
- The Electronic Transactions Act 1999

Authorisation

Christine Jeffery
 Executive Officer
 Immune Deficiencies Foundation Australia
 28/12/2018

Policy number	IDFA_Pol&Pro_Gov_Privacy and Confidentiality Agreement	Version	1
Drafted by	C Jeffery	Approved by Board on	28/12/2018
Responsible person	Board Staff Volunteers & members	Scheduled review date	03/10/2021
IDFA Board Chair	L ALEXander		

Complete your details below

I agree to abide by the IDFA Privacy and Confidentiality Agreement and Acceptance Policy and Procedures.

IDFA Board, Staff, Volunteer and Member Details:	
Name:	
Signature:	
Date:	

Authorisation

Christine Jeffery
 Executive Officer
 Immune Deficiencies Foundation Australia
 28/12/2018