

Privacy Policy



Policy number	POL014	Version	A
Drafted by	FOP Australia Board	Approved by Board on	30/07/2020
Responsible person	FOP Australia Board	Scheduled review date	30/07/2023

INTRODUCTION

The Board of FOP Australia is committed to protecting the privacy of personal information which the organisation collects, holds and administers. Personal information is information or an opinion about an identified, or reasonably identifiable, individual.

PURPOSE

The purpose of this document is to provide both an internal and external framework for FOP Australia in dealing with privacy considerations.

POLICY

FOP Australia collects and administers a range of personal information to achieve the goals of the organization. The organisation is committed to protecting the privacy of personal information it collects, holds and administers.

FOP Australia recognises the essential right of individuals to have their information administered in ways which they would reasonably expect – protected on one hand, and made accessible to them on the other. These privacy values are reflected in and supported by our core values and philosophies and also reflected in our Privacy Policy, which is compliant with the Privacy Act 1988 (Cth).

FOP Australia is bound by laws which impose specific obligations when it comes to handling information. The organisation has adopted the following principles contained as minimum standards in relation to handling personal information.

FOP Australia will

- Collect only information which the organisation requires for its primary function;
- Ensure that relevant individuals are informed as to why we collect the information and how we administer the information gathered;
- Use and disclose personal information only for our primary functions or a directly related purpose, or for another purpose with the person's consent;
- Store personal information securely, protecting it from unauthorised access; and

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Privacy Policy



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- Provide relevant individuals with access to their own information, and the right to seek its correction.

AUTHORISATION

30/07/2020
FOP Australia

Privacy Policy



1 Privacy generally

This privacy policy (**Privacy Policy**) applies to the handling of personal information by FOP Australia Ltd (ACN 603 200 871) (**FOP Australia, we, us, our**).

FOP Australia understands the importance of protecting the privacy of an individual's personal information. This Privacy Policy sets out how FOP Australia aims to protect the privacy of your personal information, your rights in relation to your personal information managed by FOP Australia and how FOP Australia collects, holds, uses, discloses and otherwise manages your personal information.

In collecting, holding, using, disclosing and otherwise managing your personal information, FOP Australia will comply with the *Privacy Act 1988* (Cth) (**Privacy Act**) and the Australian Privacy Principles (**APPs**) in the Privacy Act.

FOP Australia may, from time to time, review and update this Privacy Policy, including as a result of any new laws and technology and changes to FOP Australia's operations. An updated version of the Privacy Policy will be made available on the website at <https://fopaustralia.org/> or can otherwise be obtained by contacting us and requesting a copy.

2 What kind of personal information does FOP Australia collect

Personal information is information or an opinion about an identified, or reasonably identifiable, individual. During the provision of our services or as a result of our other interactions or dealings with you, FOP Australia may collect your personal information.

The type of information FOP Australia collects will vary depending on our particular interaction or dealing with you. However generally speaking the types of personal information FOP Australia collects may include:

- (a) [for example, if you register as a member on our website, your contact and identification information such as your name, address, telephone number, email address
- (b) [for example, if you make a donation, we may collect your Contact and Identification Information, together with payment and related information regarding your donation]; and
- (c) [for example, if you attend one of our events, we may collect your Contact and Identification Information and information relevant to your attendance at our event (which may include health information, such as information regarding your mobility needs)].

We also collect internet/technology related information from visitors to our site or users of our other online services, including the referring URL, your IP address, which browser you used to come to the site, the country, state or province, the pages of our site that you viewed during your visit and any search terms entered on our site.

Generally, we do not collect sensitive information about individuals. However, we may collect health related information about you to provide services or information to you, for example we may collect information regarding your Fibrodysplasia Ossificans Progressiva related challenges or needs so that we can provide customised information or assistance to you. If we do need to collect sensitive information about you, we will only do so with your consent or where we are

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Privacy Policy



required to do so by law. Information about your health, racial or ethnic origin, political persuasions, criminal record and religious or philosophical beliefs are all examples of sensitive information.

3 How do FOP Australia collect personal information?

Personal information you provide

FOP Australia will generally collect personal information directly from you. For example, we may collect your personal information:

- when you register as a member of our website, fill out a survey, fill out a form, submit information to our website, request information or services from us or otherwise provide us with your details;
- where you use our website or other online services or otherwise interact with us, including by way of email correspondence, phone calls and meetings;
- if you post information to any of our social media sites; and
- where you attend an event organised or sponsored by us.

Personal information provided by other people

In some circumstances, FOP Australia may be provided with your personal information from a third party if you give your consent to provide the information to us or it would be reasonably expected. For instance, we may be provided with your personal information if you donate via an online donation platform.

4 How will FOP Australia use the personal information you provide?

Generally speaking, FOP Australia collects and uses personal information so that we can provide our charitable services and information services to the public, including providing services to raise awareness of Fibrodysplasia Ossificans Progressiva, providing information and resources about Fibrodysplasia Ossificans Progressiva, providing a support network for families and individuals with Fibrodysplasia Ossificans Progressiva, fundraising and furthering research towards treatment and a cure for Fibrodysplasia Ossificans Progressiva.

Some examples of the purposes for which FOP Australia collects, holds, uses and discloses your personal information include to:

- to provide our charitable services and information services;
- to manage and administer the events, services and related activities we conduct;
- to enable us to supply you with information you request from us;
- to contact you to obtain your feedback about our services, activities and future plans; and

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Privacy Policy



- analyse information we collect so that we can administer, support and improve and develop the services we offer .

Where personal information is used or disclosed, FOP Australia takes steps reasonable in the circumstances to ensure it is relevant to the purpose for which it is to be used or disclosed. You are under no obligation to provide your personal information to FOP Australia and have the right to deal with us anonymously or using a pseudonym. However, without certain information from you, FOP Australia may not be able to provide services or information to you or may be limited in how we can interact with you.

FOP Australia uses personal information for the primary purpose of providing you with our services. We may also use it for other purposes which you might reasonably expect us to use that information, or to which you have consented. We will always obtain your consent to use sensitive information as the basis for any of our direct marketing. You authorise us to use any email address or other contract information you provide to us at any time for such above purposes, including for the purpose of direct marketing and seeking donations, which are essential for the future growth and development of FOP Australia. You can opt out of received electronic communication at any time. You agree and acknowledge that even if you opt out of receiving information about future events or marketing materials, we will still send you essential information that we are required to send you relating to the services that we provide.

5 Disclosure of personal information

FOP Australia discloses your personal information for the purpose for which FOP Australia collects it. As a result, generally FOP Australia will only disclose your personal information to a third party for a purpose set out in this Privacy Policy or where disclosure is required to meet our legal or regulatory obligations. This may include disclosing your personal information to our service providers and contractors that provide services to us (including our technology service providers) in order to assist us in providing our services.

We may also disclose your personal information to anyone authorised by you, or to whom you have provided your consent (either expressly or impliedly) or where another permitted general situation application (as defined in section 16A of the Privacy Act).

If you post information or other content to public sections of our websites or to our social media sites, you acknowledge that the information or content may be viewed by the public and/or users of the relevant website or social media site.

6 Job applicants, staff members, volunteers and contractors

In relation to personal information of job applicants, staff members, volunteers and contractors, FOP Australia's primary purpose of collection is to assess and (if successful) to engage the applicant, staff member or contractor, as the case may be.

Some examples of the purposes for which FOP Australia uses personal information of job applicants, staff members and contractors include:

- for insurance purposes; and
- to satisfy FOP Australia's legal and reporting obligations.

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Privacy Policy



Where FOP Australia receives unsolicited job applications these will usually be dealt with in accordance with the unsolicited personal information requirements of the Privacy Act.

7 Sending information to overseas recipients

FOP Australia does not currently disclose personal information to recipients located overseas or have established plans to do so. If FOP Australia is likely to disclose personal information to recipients located overseas, FOP Australia will update this Privacy Policy regarding the likely disclosures (including, if it is practicable to do so, the countries in which such overseas recipients are likely to be located).

8 Links to other websites

When you access our websites, we may provide as a convenience to you links to other websites, including sites operated by independent third parties. These links are provided as a convenience to you. Each website has its own privacy practices, as described in that site's privacy policy. Those practices may be different than the practices described in this Privacy Policy, and we encourage you to read each website's privacy policy carefully before you use or submit information to that site. Additionally, to the extent that you follow a link to a website operated by an independent third party, please be aware that we exercise no authority or control over that third party, and cannot and are not responsible for any information that you may submit to that site.

9 Management and security of personal information

FOP Australia takes steps reasonable in the circumstances to ensure that the personal information it holds is protected from misuse, interference and loss and from unauthorised access, modification or disclosure.

Your personal information will be kept on databases held on servers kept in a physically and technologically secured environment, accessed only by authorised personnel or contractors. Where personal information is held in hard copy, it will be held in controlled, access restricted premises which only authorised personnel or contractors will be permitted to access.

We have in place procedures for training our employees about their obligations under this Privacy Policy, disciplining them for failure to follow this Privacy Policy. We also have in place internal procedures to confirm general company compliance with this Privacy Policy.

FOP Australia will destroy or de-identify personal information in circumstances where it is no longer required, unless FOP Australia is otherwise required or authorised by law to retain the information.

Where you become a member of our website you may be issued with a user name and password or other sign in details. You are responsible for maintaining the confidentiality of your user name and password. You shall be responsible for all uses of your membership, whether or not authorised by you. You agree to immediately notify FOP Australia of any unauthorised use of your user name or password.

Privacy Policy



10 Accuracy of your personal information

FOP Australia takes reasonable steps in the circumstances to ensure that the personal information it holds is accurate, complete and up-to-date.

You have the right to obtain access to any personal information which FOP Australia holds about you and to correct any perceived inaccuracy, but there are some exceptions to this. If at any time you would like to access or correct the personal information that FOP Australia holds about you, or you would like more information on FOP Australia's approach to privacy, please contact the FOP Australia Privacy Officer using the details set out in section 12 below. FOP Australia will grant access to the extent required or authorised by the Privacy Act or other law and take steps reasonable in the circumstances to correct personal information where necessary and appropriate. To obtain access to your personal information, you will have to verify your identity and specify what information you require. FOP Australia may charge you a reasonable administration fee, which reflects and will not exceed the cost to FOP Australia for providing access in accordance with your request.

FOP Australia will endeavour to respond to your request to access or correct your personal information within [30] days from your request. If FOP Australia refuses your request to access or correct your personal information, FOP Australia will provide you with written reasons for the refusal and details of complaint mechanisms. If you are dissatisfied with FOP Australia's refusal to grant access to, or correct, your personal information, you may make a complaint to the Office of the Australian Information Commissioner.

11 How long will FOP Australia keep my information?

If your personal information is no longer required for the purpose for which we collected it, unless we are required or authorised by law to retain this information for a specified period of time, FOP Australia will not continue to hold the information.

Under our destruction and de-identification policies, your personal information that is no longer required will be de-identified or destroyed. In many circumstances, however it will be kept for marketing purposes if you have consented to your information being used for such purpose.

12 Enquiries and privacy complaints

If you would like further information about the way FOP Australia manages the personal information it holds or have any privacy concerns or complaints, please contact FOP Australia's Privacy Officer using the following details:

Email info@fopaustralia.org

At all times, privacy complaints will be treated seriously and dealt with promptly. FOP Australia will acknowledge your complaint within 7 days of receipt and endeavour to resolve it within [30] days, unless FOP Australia informs you otherwise.

FOP Australia's Privacy Officer will commence an investigation into your complaint. You will be informed of the outcome of your complaint following completion of the investigation. In the event

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Privacy Policy



that you are dissatisfied with the outcome of your complaint, or an extension to the time in which FOP Australia will resolve it, you may refer the complaint to the Office of the Australian Information Commissioner.

Privacy Procedure



Procedure number	PRO014	Version	A
Drafted by	FOP Australia Board	Approved by	30/07/2020
Responsible person	FOP Australia Board	Board on	
		Scheduled review date	30/07/2023

RESPONSIBILITIES

FOP Australia will from time to time nominate a Privacy Officer responsible for:

- developing, adopting and reviewing FOP Australia's Privacy Policy and Internal Privacy Compliance Procedures;
- the implementation of FOP Australia's Privacy Policy and Internal Privacy Compliance Procedures;
- monitoring changes in privacy legislation; and
- advising on the need to review or revise FOP Australia's Privacy Policy and Internal Privacy Compliance Procedures, as and when the need arises.

The Privacy Officer will report to, and may seek advice and input from, the Board of FOP Australia on matters relating to privacy compliance.

PROCESSES

1. Purpose

The purpose of this document is to provide a framework for how FOP Australia and you, as employees or volunteers of FOP Australia, must act to seek to ensure compliance with Australian privacy laws.

2. Personal information

Personal information is information or an opinion about an identified individual, or an individual who is reasonably identifiable, whether such information or opinion is true or recorded in a material form. Personal information includes sensitive information about an individual, including health information.

3. Collection of personal information

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Privacy Procedure

FOP Australia collects various types of personal information, including:

- Contact information and identification information such as name, address, phone number, email address and date of birth

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FOP Australia will:

- Only collect information that is reasonably necessary for, or directly related to, FOP Australia's functions and activities.
- Notify the relevant individuals about why we collect the information, the purpose of collection.
- Notify the relevant individuals that this information is accessible to them.
- Collect personal information from the person themselves wherever possible.
- If we collect unsolicited personal information about a person (i.e. information received by us where we have not explicitly requested it from the person or taken active steps to collect it) in circumstances in which we:
 - could not have collected that information from the person if we asked for it, we must take lawful steps to de-identify and destroy that information as soon as practicable; or
 - could have collected that information if we asked for it, the information will be treated as if it was solicited information (being, information that we have explicitly requested the person to provide).
- Only collect personal information about a person from a third party if the person has consented to it or they would reasonably expect the information to be collected by us.
- Collect sensitive information (which includes information or an opinion about an individual's health, religious beliefs, race, gender, sexual orientation, political beliefs, criminal record etc.) only with the person's consent.

4. Use and disclosure

FOP Australia will:

- Notify the relevant individuals of how the personal information we hold is used and disclosed.
- Only use or disclose information for the primary purpose for which it was collected (the primary purpose) or a secondary purpose if an exception applies, as set out below. For all other uses, FOP Australia will obtain consent from the affected person.

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Privacy Procedure

- In relation to a secondary purpose, we will use or disclose the personal information only where an exception applies, including as follows:
 - where a secondary purpose is related to the primary purpose of collection of personal information, or in the case of sensitive information, directly relates to the primary purpose of collection of sensitive information, and the individual would reasonably have expected us to use it for this purpose; or
 - where the person has consented; or
 - where certain other legal reasons exist, or disclosure is required to prevent serious and imminent threat to life, health or safety.
- In relation to personal information which has been collected from a person, we will use the personal information for direct marketing only where that person would reasonably expect it to be used for this purpose, and FOP Australia has provided an opt out option which has not been taken up.
- In relation to personal information which has been collected other than from the person themselves, or from the individual directly but the individual would not reasonably expect the information to be used for the purpose of direct marketing, only use the personal information for direct marketing if the person whose personal information has been collected has consented (and they have not taken up the opt-out option).
- State in FOP Australia's Privacy Policy whether the information will be disclosed to an overseas recipient (which may include providers of services).
- Release information to third parties where it is requested by the person concerned.

5. Access to personal information and data quality

FOP Australia will:

- On request, provide all individuals with access to their personal information, except if a ground for refusal applies (for example, if providing access to information would pose a serious threat to life or health or it is authorised by law to refuse).
- Take reasonable steps to ensure the information FOP Australia collects, uses or discloses is accurate, complete, up to date, and relevant to the functions we perform.
- If a person is able to establish that their personal information is not accurate, take steps to correct it. FOP Australia may allow a person to attach a statement to their information if FOP Australia disagrees it is inaccurate.
- Where for a legal or other reason we are not required to provide a person with access to the information, consider whether a mutually agreed intermediary would allow sufficient access to meet the needs of both parties.

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Privacy Procedure



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- Make no charge for making a request for personal information, but may charge a reasonable administration fee for providing access in accordance with that request and correcting any information.

6. Storage

FOP Australia will:

- Notify relevant individuals of how the personal information FOP Australia holds is protected.
- Implement and maintain steps to ensure that personal information is protected from misuse and loss, unauthorised access, interference, unauthorised modification or disclosure.
- Before disclosing any personal information to an overseas recipient (including a provider of IT services, such as servers or cloud services), establish that they are privacy compliant.
- Have systems which provide sufficient security for the protection of personal information.
- Ensure that FOP Australia's data is up to date, accurate and complete.

7. Destruction and de-identification

FOP Australia will:

- Destroy or de-identify personal information which is no longer required to be kept for the purpose for which it was collected, including from decommissioned laptops and mobile phones, subject to any laws that require or authorise FOP Australia to retain some information for a specified period of time (including laws relating to health information).
- FOP Australia will only destroy records in accordance with the organisation's Board's Records Policy.
- De-identify information by changing it to a pseudonym or treat it anonymously if required by the person whose information FOP Australia holds and will not use any government related identifiers unless they are reasonably necessary for our functions.

8. Openness and transparency

FOP Australia will:

- Ensure the relevant individuals are aware of FOP Australia's Privacy Policy and its purposes.
- Make this information freely available in relevant publications and on the organisation's website.

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Privacy Procedure



9. Enquiries and complaints

All privacy related complaints and queries must be directed to the Privacy Officer as soon as practicable and dealt with in accordance with the FOP Australia Privacy Policy.

10. Data breach

In the event of a data breach or suspected data breach involving the personal information of individuals, the Privacy Officer should be notified immediately and the following steps should be followed:

- contain the data breach and if there are reasonable grounds to suspect there may have been an 'eligible data breach', conduct a preliminary assessment within 30 days;
- evaluate the risks associated with the suspected or actual data breach;
- consider whether FOP Australia is required to notify affected individuals and the and the Office of the Australian Information Commissioner of the relevant data breach; and
- take steps to prevent future data breaches.

Generally speaking, an **eligible data breach** arises when the following criteria are met:

- there is unauthorised access to, or disclosure of, personal information held by FOP Australia (or personal information is lost in circumstances where unauthorised access or disclosure is likely to occur);
- the access, disclosure or loss is likely to result in serious harm to any of the individuals to whom the information relates; and
- FOP Australia has been unable to prevent the likely risk of serious harm with remedial action.

RELATED DOCUMENTS

- Board Records Policy

AUTHORISATION

30/07/2020

FOP Australia

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