

# VICTORIAN CLINICAL GENETICS SERVICES

## PRIVACY POLICY

The Victorian Clinical Genetic Services (**VCGS, we, our or us**) recognises the importance of protecting the privacy and rights of individuals in relation to their personal information. This document is VCGS's Privacy Policy and applies in respect of the information collected and used by both VCGS and our related bodies corporate (including Murdoch Childrens Research Institute (**MCRI**)). This policy has been developed in accordance with the *Privacy Act 1988* (Cth) (**Privacy Act**) as amended from time to time. VCGS also complies with the Health Privacy Principles as set out in the *Health Records Act 2001* (Vic) where applicable and as amended from time to time.

This Privacy Policy explains how VCGS handles personal information relating to individuals with whom VCGS interacts, including patients, research participants, donors, customers, medical professionals, consultants and contractors (referred to in this policy as **you**). This Privacy Policy does not apply to our acts and practices directly related to a current or former employment relationship between us and an employee, or to an employee record held by us relating to the employee.

### 1. Personal information and sensitive information

The expression 'personal information' has the meaning given by the Privacy Act. It is information or an opinion that can be used to personally identify you. This may include your name, address, telephone number, email address and profession or occupation. If the information we collect personally identifies you, or you are reasonably identifiable from it, the information will be considered to be personal information.

Some personal information is also 'sensitive information'. Sensitive information has the meaning given by the Privacy Act. Sensitive information is information about your racial or ethnic origin, your political opinion, your political association, your religious beliefs/affiliations, your philosophical beliefs, whether you are a member of a trade or professional association or trade union, your sexual orientation/practices, your criminal record or your health information (including genetic information or biometric information).

### 2. What personal information does VCGS collect and hold?

We only collect personal information if it is reasonably necessary for one or more of our functions or activities. We may collect the following types of personal information:

- name;
- date of birth;
- mailing or street address;
- email address;
- telephone or facsimile number;
- occupation or job title;
- health and medical history or information;
- information about your dependents or your pregnancy (where reasonably necessary);
- bank account or credit card details if you are making a payment for our services or donation; and
- photographs of you or your dependents at a VCGS fundraising or other event.

Where the personal information is also sensitive information, we will only collect it with your prior consent. Usually we will require your consent to be in writing.

We may receive personal information which we did not ask for (i.e. unsolicited information). If this occurs, within a reasonable period of time we will determine whether we could have collected the information by seeking it from you. If we determine that we could not have collected that information from you, we will destroy the information or de-identify it where it is otherwise lawful to do so.

We may also collect information from time to time that is not personal information because it does not identify you or any other individual. For example, we may collect anonymous answers to surveys or aggregated information about how people use our website and services.

### **3. How and when does VCGS collect personal information?**

We collect your personal information directly from you unless it is unreasonable or impracticable to do so. If we collect your personal information from someone other than you, we will take reasonable steps to ensure that you are or have been made aware of what information has been collected, and the purpose of that collection. When collecting personal information from you, we may collect it in ways including:

- during conversations between you and our staff (which includes paid employees and volunteers);
- when you complete documentation;
- when you participate in the services we provide or other research activities; or
- through your access and use of our website.

Our website Privacy Policy is set out at [www.vcgs.org.au/about/privacy](http://www.vcgs.org.au/about/privacy). That policy applies to your use of our website and details how your personal information may be used by us when provided through our website.

### **4. For what purposes does VCGS collect, hold and use personal information?**

We will only collect and/or use your personal information (including health information) to the extent that this is necessary for one or more of the following activities:

- to provide services to you;
- to verify your identity, respond to your requests or as otherwise directed by you;
- to provide you with news, information and material in relation to services of the Institute and our related bodies corporates (including MCRI) if requested by you;
- to undertake medical research as consented to by you;
- to undertake general research or other reasonably related research activities for VCGS or our related body corporates (including MCRI), including surveys and polls and other reasonably related research activities;
- for the administrative, employment, planning, service development, quality control and research purposes of VCGS;
- to update our records and keep your contact details up to date;
- to process and respond to any complaint made by you;
- to comply with any law, rule, regulation, lawful and binding determination, decision or direction of a regulator, or in co-operation with any governmental authority in Australia;
- to promote programs and activities of VCGS or our related bodies corporate (including MCRI), including fundraising, corporate philanthropy and education; and
- otherwise as permitted by law.

We only collect such personal information that we need for these primary purposes or for other (secondary) purposes that are related to a primary purpose. If we hold personal information about you that was collected for a particular purpose (i.e. one of the purposes listed above, being the primary purpose), we will not use or disclose the information for another purpose (i.e. a secondary purpose) without your consent, unless you would reasonably expect us to use it for the secondary purpose, or it is required by law.

In relation to the use of your personal information to provide you with information about our programs, activities and fundraising, you may at any time request us not to provide you with any direct marketing and fundraising communications or publications. We will provide you with a simple means to opt-out of receiving such correspondence from us. You may elect to opt-out from receiving direct marketing and fundraising information at any time, by contacting us at the contact details below or, in the case of electronic correspondence, by selecting any unsubscribe option. Please note that you cannot opt-out of receiving contractual notifications such as changes to our terms and conditions for the supply of goods or services or other important information. In relation to sensitive information, we will not use or disclose this for the purpose of direct marketing unless you have expressly consented.

### **5. What happens if you do not provide us with the personal information we request?**

You have the right to not identify yourself, including the right to not provide us with your personal information.

If you do not provide us with the personal information described above, we may not be able to provide the requested services to you, either to the same standard or at all, and we may not be able to provide you with information about services that you may want, including information about related services.

### **6. How does VCGS securely hold your personal information?**

We will take reasonable steps to protect all personal information which we hold from misuse or loss and from unauthorised access, modification or disclosure. We may hold your information in either electronic or hard copy form. Personal information is destroyed or de-identified by us when it is no longer needed for the primary purposes (or any related secondary purposes) set out in this privacy policy.

Risks are mitigated through VCGS's commitment to de-identifying or destroying any un-required personal information where possible.

You should be aware when using our website that no data transmission over the Internet can be guaranteed as totally secure. Although we strive to protect such information, we do not warrant the security of any information that you transmit to us over the Internet (including through our website), and you do so at your own risk.

### **7. Who can VCGS disclose your personal information to?**

We may provide your personal information (including your health information), to:

- our staff, which include our paid employees, volunteers and contractors;
- our professional advisors;
- our related bodies corporate (including MCRI), partners, affiliates, contractors and consultants who assist us in providing services to us and are required by us to protect your personal information;
- any organisation for any authorised person with your express consent;
- a person or organisation to whom we are compelled by law, or otherwise permitted by law, to provide your information; or
- your organisation, if you are acting on behalf of an organisation.

If we refer you to a third party service provider, that service provider may also collect and store your personal information. We make no representation or warranties in relation to the privacy practices of any third party service provider and we are not responsible for their collection, use or disclosure of your personal information. Third party service providers are responsible for informing you about their own privacy practices.

## **8. Does VCGS disclose personal information to anyone outside Australia?**

We may be required, from time to time, to disclose your personal information to our international partners and research affiliates for performance of the activities detailed in section 4 of this Privacy Policy. The locations of our international partners and research affiliates are detailed at section 13 (end of this document). When you provide us with your personal information, you consent to such disclosure as reasonably necessary, and agree that APP8.1 does not apply. Notwithstanding this, we will take reasonable steps to ensure that the overseas recipient observes confidentiality in a manner consistent with this Privacy Policy and requirements of the Privacy Act. To the extent that it is reasonable and practical for us to do so, we will use reasonable endeavours to de-identify any such personal information prior to overseas disclosure.

## **9. How can you access and correct your personal information?**

You may request access to any personal information we hold about you at any time by contacting the VCGS Privacy Officer (see details in section 12 below). Where we hold information that you are entitled to access, we will take reasonable steps to provide you with suitable means of accessing it.

There may be instances where we cannot grant you access to the personal information we hold. For example, we may need to refuse access if granting access would interfere with the privacy of others or if it would result in a breach of confidentiality. If that happens, we will give you written reasons for any refusal.

We will take reasonable steps to ensure that any personal information that we have collected is accurate, up-to-date and complete. We also take reasonable steps to ensure that any personal information we use or disclose is accurate, up-to-date, complete, and relevant having regard to the purpose of the use or disclosure.

If you believe that personal information we hold about you is incorrect, incomplete or inaccurate, then you may request us to amend it. We will consider whether the information requires amendment. If we agree, we will take reasonable steps to correct the information held. In some circumstances where we correct or update a record, we may still require retention of the original record. If we do not agree that there are grounds for amendment then we will add a note to the personal information stating that you disagree with it.

## **10. What is the process for complaining about a breach of privacy?**

If you believe that your privacy has been breached, please contact the VCGS Privacy Officer (see details in section 12 below) and provide details of the incident so that we can investigate it.

We may require any complaint to be made in writing first. We will then endeavour to respond to your complaint within 30 days. If we are unable to resolve your complaint to your satisfaction, a complaint can also be made to the Office of the Australian Information Commissioner.

## **11. Changes to this Privacy Policy**

We reserve the right to change, modify or update this Privacy Policy (or our website Privacy Policy), from time to time and without liability to you, on how we handle personal information or the types of personal information which we hold, by publication of the revised version. Any revision to our website Privacy Policy will be published on our website. The revised version shall take effect immediately upon publication.

## **12. Contacting us about an enquiry or complaint**

If you have an enquiry about this privacy policy, or a complaint regarding the treatment of your privacy or a possible breach of your privacy, please contact the VCGS Privacy Officer at:

Mrs Amandine Philippart de Foy  
Murdoch Childrens Research Institute  
Royal Children's Hospital  
50 Flemington Road Parkville VIC 3052

Email: [amandine.philippart@mcri.edu.au](mailto:amandine.philippart@mcri.edu.au)  
P: +61 3 9936 6337

We will treat your enquiry or complaint confidentially. One of our staff will contact you within a reasonable time after you have made contact with us to discuss your enquiry or complaint and outline options regarding how it may be dealt with. We will aim to ensure that any complaint is resolved in a timely and appropriate manner.

## **13. Locations of our international partners and research affiliates**

Our international partners and research affiliates are located worldwide including, but not limited to:

- New Zealand;
- USA;
- Canada;
- EU (including, but not limited to, United Kingdom, France, Italy, Finland, Sweden, Netherlands, Cyprus);
- Japan;
- Singapore;
- Hong Kong;
- Indonesia;
- Vietnam;
- Fiji;
- Thailand;
- Qatar;
- Mongolia;
- Lao PDR;
- Papua New Guinea;
- Nigeria;
- The Gambia;
- Brazil; and
- Chile.