

PRIVACY AND PERSONAL DATA STORAGE POLICY

The Garvan Institute of Medical Research and the Garvan Research Foundation (**Garvan**) are committed to ensuring the privacy and confidentiality of your personal information. The Garvan complies with the Commonwealth Privacy Act and other relevant state laws in relation to the management of personal information.

The Garvan Privacy Policy explains in general terms how the Garvan protects the privacy of your personal information. The principles set out in this policy will apply to personal information you provide to us (including via our website) and to personal information we collect about you under any other agreement or arrangement.

This policy does not apply to the Garvan's employee records.

How the Garvan collects and handles your personal information

We generally collect your personal information directly from you. For example, we may collect personal information about you when we deal with you over the phone or when you have contact with us in person or over the Internet.

If we collect information about you from a third party, we will take reasonable steps to contact you and ensure that you are aware of the purposes for which we are collecting your personal information as well as advising you of other persons or organisations to which we might give your personal information.

Generally the kinds of personal information we collect about you may include your name, address, telephone numbers, e-mail address, research areas of interest, event attendance and payment (including credit card) details. We collect information from our donors and supporters including information about your donation history and activities that you have indicated you may be interested in being involved with.

We use this information to enable us to send you newsletters and bulletins as well as information about research, education and fundraising events and activities. We may use your information to contact you to seek financial support for medical research conducted at the Garvan.

We may also collect personal information when we are canvassing recruitment of staff and PhD students. Generally speaking, we will collect personal information that you supply to us as part of this process and use it for the purposes of assessing applications and proposals.

We will only collect personal information necessary to conduct our business activities.

From time to time, we may share contact details of our financial supporters with other like-minded charities to contact you with fundraising materials. In return they help us to reach more generous supporters. This really helps us to inform more people about the value of medical research. We will not do this if you advise us you do not wish it. If you do not wish to receive communication from another charity, please call 1300 73 66 77.

We will not directly disclose your personal details to any other non-charity third party except in cases where names and contact details will be provided to external contractors who assist with mailing our newsletters and sending other information on our activities to you. On such occasions contractors who have access to personally identifiable information are required to protect this information in a manner that is consistent with this Privacy Policy by, for example, not using the information for any purpose other than to carry out the services they are performing for the Garvan.

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Participation in research and clinical trials at the Garvan

In order to conduct research and clinical trial activities, the Garvan may collect your personal information including health information. In addition to your name and address, this information may also include:

- your medical history including (where clinically relevant) a family medical history;
- your Medicare number and private health insurance information;
- current medications or treatments used by you;
- the name of any care provider, health service provider or medical specialist to whom we refer you back or who has referred you to us, copies of any referrals and reports; and
- test results and samples.

This information is used to record your involvement in clinical trials and other research activities undertaken by the Garvan, to process the results of research and clinical trials and to contact you regarding participation in future studies. It is not used for fundraising purposes and your details are not passed onto the Garvan Research Foundation (the marketing and fundraising arm of the Institute).

From time to time we may collate statistical data from the information we have collected. In these cases, the data will be de-identified and aggregated before it is disclosed to third parties.

All research and clinical trials undertaken at the Garvan are approved by the St Vincent's Hospital Human Research Ethics Committee. Patients enrolled in trials or research will be given information detailing how health information will be handled by the Garvan.

Security of your personal information

We take all reasonable steps to ensure the security of the personal information we hold from unauthorised access, modification or disclosure. We maintain physical security over our paper and electronic data stores and premises, such as locks and security systems.

Your personal information may be stored in hardcopy documents, as electronic data, or in the Garvan's software or systems. We maintain computer and network security; for example, we use firewalls (security measures for the Internet) and other security systems such as user identifiers and passwords to control access to our computer system. Paper records are stored in locked filing cabinets in secure areas.

Donations and registrations made on Garvan websites use SSL security and credit card data is stored using PCI compliant systems.

Anonymity

Where lawful and practicable, you will be given the option to deal with us without identifying yourself (eg when inquiring about the activities that the Garvan undertakes).

Individuals should be aware that contact details are required in order for the Garvan to issue a tax-deductible receipt.

While we seek to recognise the contributions of our donors and supporters in our publications, individuals wishing to remain anonymous in our publications and at other public forums should advise this in writing to the CEO of the Garvan Research Foundation.

Gaining access to information we hold about you

The Garvan will, on request, provide you with information we hold about you, unless there is an exception which applies under relevant privacy laws. Access can only be denied in certain circumstances.

Unless there is an exception which applies under privacy laws we will provide you with a photocopy and/or printout of information held within 14 days. No charge will be made for this service.

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Keeping your personal information up-to-date

We take reasonable steps to ensure that your personal information is accurate, complete and up-to-date whenever we collect or use it.

If you find that the personal information we hold about you is inaccurate, incomplete or out-of-date, please contact us immediately and will take reasonable steps to either correct this information or, if necessary, discuss alternative action with you.

Our website

Visiting www.garvan.org.au generates the following statistics:

- your server address;
- your top level domain name (.com, .gov, .au, .uk etc);
- the pages you access and documents downloaded;
- any keywords or search words you enter; and
- the type of browser you are using.

These statistics are gathered so we can improve our website for future visitors. This information does not make it possible for you to be identified.

If you send us an email, your email address (together with any other information you send us) will only be used for the purpose for which you have provided it, except where you give consent for another purpose. This site does not provide facilities for the secure transmission of information across the Internet. Users should be aware that there are inherent risks in transmitting information across the Internet.

If you do not click 'remember me' or log in, "cookies" are not employed on the websites except for those generated when you use the search engine. These are destroyed at the end of your browser session. No information about you is stored at the end of your browser session. (A "cookie" is information that a web site puts on your hard disk so that it can remember something about you at a later time.)

"Cookies" are used when you select 'remember me' or register or log in on the giving.garvan.org.au website, in order to provide you with a better level of service when using our website and save you time. When you log in to our website, your details are recorded as requested on our secure database and your activities (eg your fundraising email texts) are recorded in order to provide you with high quality service when using the site.

We may create links to third party websites. The Garvan is not responsible for the content or privacy practices employed by websites that are linked from our website.

Changes to the Garvan privacy policy

The Garvan Privacy Policy may be amended from time to time. You can access the most up to date copy by visiting our website.

Addressing your concerns

if you have a query on how your personal information is collected or used, or any other query relating to the Garvan Privacy Policy, please contact:

Privacy Officer, Garvan Institute of Medical Research
384 Victoria Street, Darlinghurst NSW 2010
Tel: 02 9295 8100 Fax: 02 9295 8101
Email: generalinfo@garvan.org.au

We will respond to your query or concern as soon as possible and will try to resolve any complaint within 10 working days. If this is not possible, we will contact you within that time to let you know how long we estimate it will take to resolve your concern.

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