

## NeuroEndocrine Cancer Australia – Privacy Policy

NeuroEndocrine Cancer Australia (formerly the Unicorn Foundation) is an Australian not-for-profit medical charity focused on neuroendocrine tumours. This is the privacy policy for NeuroEndocrine Cancer Australia. NeuroEndocrine Cancer Australia recognises the importance of your privacy and understands that the security of your personal information is important to you. We are committed to protecting the personal information that you provide to us.

This Privacy Policy explains how NeuroEndocrine Cancer Australia manages the personal information that we collect, hold, use and disclose and how to contact us if you have any further queries about our management of your personal information. This privacy policy applies to you only to the extent that the collection and handling of your personal information by NeuroEndocrine Cancer Australia is subject to the Privacy Act 1988 (Cth) ("Privacy Act").

### Policy Statement

NeuroEndocrine Cancer Australia is committed to protecting the privacy of the personal information and sensitive information which it collects and holds. NeuroEndocrine Cancer Australia must comply with the Australian Privacy Principles under the Privacy Act which governs the way in which organisations (such as NeuroEndocrine Cancer Australia ) hold, use and disclose personal information (including your sensitive information). The purpose of this Privacy Policy is to explain:

- a. The purposes for which NeuroEndocrine Cancer Australia collects, holds, uses and discloses personal information;
- b. The kinds of information that NeuroEndocrine Cancer Australia may collect about you and how that information is held;
- c. How NeuroEndocrine Cancer Australia collects and holds personal information;
- d. How you can access the personal information NeuroEndocrine Cancer Australia holds about you and seek to correct such information; and
- e. The way in which you can complain about a breach of your privacy and how NeuroEndocrine Cancer Australia will handle that complaint.

### Background

Where the collection or handling of your personal information by NeuroEndocrine Cancer Australia is subject to the Privacy Act, NeuroEndocrine Cancer Australia must comply with the requirements of that Act. The Privacy Act regulates the manner in which personal information is handled throughout its life cycle, from collection to use and disclosure, storage, accessibility and disposal.

Personal information is information or an opinion about an identified individual, or an individual who is reasonably identifiable, whether the information or opinion is true or not, and whether the information or opinion is recorded in a material form or not.

Special provisions apply to the collection of personal information about a person's race, ethnic origin, political opinions, membership of political, professional or trade associations, religious or philosophical beliefs, sexual preferences and criminal history.

In this privacy policy, all references to personal information includes sensitive information unless indicated otherwise.

### **Why do we collect your personal information?**

The Privacy Act generally requires NeuroEndocrine Cancer Australia to use personal information only for the primary purpose for which it is collected, or for secondary purposes which are related (or directly related in the case of sensitive information) to the primary purpose.

In general, NeuroEndocrine Cancer Australia collects, holds, uses and discloses personal information for the following purposes:

1. Support services: to provide you with information and support services, and to evaluate and report on these services.
2. Research: to conduct and/or fund research into NET cancers, including diagnosis, treatment and cures, improvement in quality of life and supportive care.
3. Health promotion: to provide you with information about living well with a NET cancer, and to seek your support for specific campaigns that may relate to a NET cancer.
4. Volunteering and other support: to invite you to assist us with community fundraising, raising awareness (Net Cancer Day), advocacy and other activities, where community assistance is required.
5. Marketing: to communicate with you about donations, products, services, campaigns, causes, news, events and possible media opportunities.
6. Other issues: communicating with you in relation to our operations and organisational impact, to verify your identity, to improve and evaluate our programs and services and to comply with relevant laws.

Our range of services and our functions and activities may change from time to time.

If you provide your email address, telephone and/or mobile phone number, you also consent to NeuroEndocrine Cancer Australia using your email address telephone and/or mobile phone number to contact you (including by telephone call, SMS or email) for any of the above purposes.

### **What personal information does NeuroEndocrine Cancer Australia collect?**

In the course of our activities, NeuroEndocrine Cancer Australia may collect personal

information about you that is necessary for us to perform our functions and activities.

NeuroEndocrine Cancer Australia will only collect personal information about you by lawful and fair means and not in an unreasonably intrusive manner.

The types of personal information we may collect and hold may vary depending on the nature of our interaction with you and may include:

- Identifying and contact information (such as name, age, address and telephone number);
- Health information such as information about your health condition
- Personal information or an opinion about your physical or mental health, or your wishes about future provision of health services
- Personal information or opinion about your racial or ethnic origins, political opinions or associations, philosophical or religious beliefs or affiliations, sexual preferences or practices, criminal record, health information.

### **How does NeuroEndocrine Cancer Australia collect personal information?**

NeuroEndocrine Cancer Australia may collect your personal information in a number of ways.

If you are a patient, NeuroEndocrine Cancer Australia typically collects your personal information directly from you but may also collect your personal information from your treating healthcare professionals.

If you are providing voluntary services, then NeuroEndocrine Cancer Australia may collect your personal information from you directly.

If you are a donor or supporter of NeuroEndocrine Cancer Australia we will collect personal information from you directly.

How does NeuroEndocrine Cancer Australia hold your personal information and manage the data quality and security of your personal information?

We take all reasonable steps to protect all of the personal information we hold from misuse, interference and loss, and from unauthorised access, modification or disclosure. Your personal information will be stored on a password protected electronic database, which may be on our database, a database maintained by a cloud hosting service provider or other third party database storage or server provider. Backups of electronic information are written to drives which are stored offsite.

Hard copy information is generally stored in our offices, which are secured to prevent entry by unauthorised people. Any personal information not actively being used is archived, usually for 7 years.

Where personal information is stored with a third party, we have arrangements which require those third parties to maintain the security of the information. We take reasonable steps to protect the privacy and security of that information, but we are not liable for any unauthorised access or use of that information. Your personal information will stay on the database indefinitely until you advise you would like it removed, unless we de-identify it or destroy it earlier in accordance with privacy law requirements.

### **Does NeuroEndocrine Cancer Australia transfer personal information overseas?**

We use data hosting facilities and third party service providers to assist us with providing our goods and services. As a result, your personal information may be transferred to, and stored at, a destination outside Australia, including but not limited to New Zealand, Netherlands, China, Singapore, Hong Kong, Ireland, Canada, United States of America and the United Kingdom.

We take such steps as are necessary in the circumstances to ensure that any overseas third party service providers we engage do not breach the Australian Privacy Principles, including through contractual arrangements.

If your personal information is collected using a collection notice that references this Privacy Policy, you are taken to consent to the disclosure, transfer, storing or processing of their personal information outside of Australia. You also acknowledge and understand that by providing such consent that we will not be required to take such steps as are reasonable in the circumstances to ensure such third parties comply with the Australian Privacy Principles.

### **How can you access or correct your personal information and contact NeuroEndocrine Cancer Australia?**

Please contact us if you would like to seek access to or request that we correct the personal information that we hold about you:

- By mail: Simone Leyden, Chief Executive Officer, NeuroEndocrine Cancer Australia, PO Box 384 Blairgowrie, Victoria 3942
- By telephone: 0419 871 975
- By email: [simone.leyden@neuroendocrine.org.au](mailto:simone.leyden@neuroendocrine.org.au)  
(<mailto:simone.leyden@neuroendocrine.org.au>)

NeuroEndocrine Cancer Australia will, upon your request, and subject to applicable privacy laws, provide you with access to your personal information that is held by us. However, we request that you identify, as clearly as possible, the type(s) of information requested. We will deal with your request to provide access to your personal information within 30 days and you agree we may charge you our reasonable costs incurred in supplying you with access to this information.

Your rights to access personal information are not absolute and privacy laws dictate that we

are not required to grant access in certain circumstances such as where:

- access would pose a serious threat to the life, safety or health of any individual or to public health or public safety
- access would have an unreasonable impact on the privacy of other individuals the request is frivolous or vexatious
- denying access is required or authorised by a law or a court or tribunal order
- access would be unlawful, or
- access may prejudice commercial negotiations, legal proceedings, enforcement activities or appropriate action being taken in respect of a suspected unlawful activity or serious misconduct.

If we refuse to grant you access to your personal information, we will provide you with reasons for that decision (unless it is unreasonable to do so) and the avenues available for you to complain about the refusal.

Participants in research studies should note that access to personal information such as DNA sequences is not generally granted, in accordance with the first exception above. This is notified to you, where applicable, at the time of committing to the research study.

### **What happens if you don't provide all this information?**

If you do not provide some or all of the personal information requested, we may not be able to offer you services or provide you with information about our causes, events, programs and projects.

Using a pseudonym or engaging with us anonymously

Where practicable, you will be given the opportunity to engage with us on an anonymous basis, or using a pseudonym.

### **Opting out of communications**

Where we use your personal information to communicate with you by post, email or telephone, we will provide you with an opportunity to opt-out of receiving such information. By electing not to opt-out, we will assume we have your implied consent to receive similar information and communications in the future. We will always ensure that our opt-out notices are clear, conspicuous and easy to take up.

If you do not wish to receive communications from us, please contact us at NeuroEndocrine Cancer Australia, GPO Box 384 Blairgowrie VIC 3942 or [info@neuroendocrine.org.au](mailto:info@neuroendocrine.org.au).

### **How NeuroEndocrine Cancer Australia handles complaints?**

If you have any concerns or complaints about the manner in which your personal information has been collected or handled by NeuroEndocrine Cancer Australia, please advise us of your concern or complaint in writing and send it to the Chief Executive Officer using the mailing

address set out above. Your concern or complaint will be considered or investigated and we will endeavour to respond to your complaint within 14 days.

It is our intention to use our best endeavours to resolve any complaint to your satisfaction. However, if you are unhappy with our response, you may contact the Office of the Australian Information Commissioner who may investigate your complaint further.

### **Further Information**

Further information about the application of the Privacy Act can be found at the website of the Office of the Australian Information Commissioner at [www.oaic.gov.au](http://www.oaic.gov.au).

If you would like a downloadable copy please [click here](#)