

## The Transplant Network - Privacy Policy

**Last updated: 17 March 2023**

The Transplant Network Incorporated (ABN 58 231 065 432) (TTN) is committed to managing personal information in accordance with the Australian Privacy Principles under the *Privacy Act 1988* (Cth) (**Privacy Act**) and other applicable privacy laws.

In this Privacy Policy, "we" and "us" refers to TTN and "you" refers to any individual about whom we collect personal information.

We take protecting your privacy very seriously and we want to be open and transparent with you about how we handle your personal information. This Privacy Policy describes the ways in which we collect, hold, store, use and share your personal information. If you have any questions about our Privacy Policy, or about the ways we handle your personal information, please contact us using the details set out below.

### ABOUT TTN

TTN is a registered charity which was established to improve the lives of those who undergo a transplant and everyone they will come to rely on throughout that experience.

TTN seeks to build a supportive community where all benefit from the personal testimonies of others. To that end, patients, families, donors and doctors have the opportunity to speak and tell their own powerful stories. This avenue of personal contribution both empowers and connects patients every step of the way.

Our mission is to **inform**, **empower** and **support** transplant patients and their families to be well equipped to navigate their own transplant journey (**Objectives**). To fulfill these Objectives, we may ask to collect a broad range of personal information from you about your own experiences or to provide products and services to you.

### WHEN DOES THIS PRIVACY POLICY APPLY AND WHAT IS IT?

This document sets out how we manage your personal information and is referred to as our Privacy Policy. It is divided into a number of sections and in addition to explaining how we manage personal information it also provides answers to commonly asked questions.

Our Privacy Policy explains how we collect, store, process, use and disclose personal information (including personal information we collect, and personal information submitted to us, whether offline or online). For example, this can include:

- information we collect when an individual participates in an interview with TTN; and
- information we may collect when you interact with us (including when you visit our website (<https://thetransplantnetwork.com.au>), or contact and communicate with us via our social media channels (such as via Facebook, Instagram or LinkedIn), phone or online).

Other terms and conditions may also apply to you, such as:

- our online TTN Terms and Conditions (as applicable to you); and
- collection notices and privacy statements which may be provided to you at the time your personal information is collected.

## WHAT IS PERSONAL INFORMATION?

Personal information is defined in the Privacy Act as ‘information or an opinion about an identified individual, or an individual who is reasonably identifiable:

- whether the information or opinion is true or not; or
- whether the information or opinion is recorded in a material form or not’.

In this Privacy Policy, whenever we use the term “personal information”, we are referring to this legal definition.

This is a very broad definition, however some simple examples of personal information include your name and date of birth. It is important to be aware that personal information also includes sensitive information (such as your health information) and financial information (such as your debit card number).

## WHAT INFORMATION DO WE COLLECT ABOUT YOU AND HOW DO WE COLLECT THIS INFORMATION?

*How do we collect personal information?*

TTN generally collects personal information directly from you. We may also collect personal information about you from other sources, for example your social media (such as Facebook, Instagram or LinkedIn) or your family member and friends.

In some cases you may provide us with personal information which relates to another person (for example, a family member involved with your transplant journey). If you do so, you agree that you have received permission from these individuals for us to collect, use, and share, their personal information in accordance with this Privacy Policy. You should also let them know about our Privacy Policy (including the information in this Privacy Policy).

In summary, we may collect your personal information when you:

- share your transplant story with us (including if you conduct an interview with us);
- connect with us as a medical professional;
- partner with us as a corporate partner of TTN;
- subscribe to TTN’s newsletter;
- donate to TTN; or
- otherwise interact with us via phone or online (including through our website or our social media channels), such as when you contact us to participate in TTN, make an enquiry or give us feedback.

*What information do we collect?*

The type of personal information that we collect will typically include:

- your name, e-mail, postal address and other contact details;
- if you conduct an interview with us, photographs and recordings (audio and/or visual) of you;
- any additional personal information you provide to us, or authorise us to collect, as part of your interaction with TTN, including your gender, date of birth, job title and previous employment history.

We may also collect sensitive information and health information if you decide to provide it to us (for example, information about your general health, medical conditions and your transplant). Where we do so, we will do so in accordance with this Privacy Policy and applicable laws.

You can decide whether and how much personal information you would like to provide to TTN and you can always decline to give TTN any personal information we request. If you have any concerns about personal information we have requested, please let us know.

*If you are under 15*

TTN encourages people of all ages to share their transplant journey, however it is important that you only provide us with your personal information if you are 15 years of age or older. If you are under 15 years of age, you must ensure your parent or guardian provides your personal information to us on your behalf.

## **CAN YOU DEAL WITH US WITHOUT PROVIDING YOUR NAME OR OTHER PERSONAL INFORMATION?**

For some types of interaction TTN will provide you with the opportunity of remaining anonymous or using a pseudonym (for example, when making a donation). However, this may limit our ability to engage with you.

Most of the time, you will have the option of not providing your name, or using a fake name, when you deal with us (where it is lawful and practicable). This includes for example, when you make a general enquiry.

In some circumstances, however, it will not be practicable for us to deal with you anonymously (for example, if you make a donation). In these circumstances, if we do not collect your personal information, we may not be able to provide you with the products and/or services you have asked for.

## **WHY DO WE COLLECT, STORE AND USE YOUR PERSONAL INFORMATION?**

We collect personal information that is necessary to achieve our Objectives, and to carry out our business operations.

The main purposes for our collection of personal information are to build and grow TTN. This includes:

- building a network of patients, families, donors and doctors, where all benefit from the personal testimonies and transplant journeys of others;
- providing this network with useful and insightful multimedia content (including via videos and online content);
- sharing this content and helpful information across the network; and
- raising funds to assist with the development and growth of TTN.

We may use your personal information for purposes which are incidental to achieving the Objectives, or for other purposes which are within your reasonable expectation or permitted by law.

The purpose for which we usually collect, store, and use your personal information depends on how you interact with us (for example, whether you are a subscriber of our content, provide a donation, participate in an interview with us or otherwise contribute to or participate in TTN), but may include to:

- manage and run TTN, including to prepare, create and publish content on TTN's website and build connections across the network (such as to connect organ donors and donor recipients for those individuals to share their transplant experiences);
- administer, manage and communicate with you about TTN and its products and services (including about any new content or resources made available and how to support TTN in its Objectives);
- improve our products and services, and your experience with us;
- do business with you (if you interact with us on a commercial basis, such as if you are a service provider, contractor or supplier to us, or if you otherwise interact with us on a commercial basis); and
- manage and improve our operations (such as to process and manage donations and funds, to manage, monitor, plan and evaluate our products and services, to test and maintain

information technology systems (and investigate any incidents that may occur), to handle and respond to any complaints or general enquiries (including in relation to an individual's transplant journey).

## **WHERE DO WE SHARE YOUR PERSONAL INFORMATION AND WHY?**

We may share your information with third parties:

- for the reasons for which we collect, store and use that information (see above);
- for other purposes explained at the time we collect your personal information; or
- where we are otherwise allowed or required to do so under law.

Some of the third parties we may share your information with include the following:

- other members of TTN, including to share your transplant story (if you have shared this with us) and to connect you with other members of the network;
- our partners, suppliers and entities we do business with (who assist us with providing our products and services), such as partners who may offer you special offers and discounts;
- our service providers and advisors (who assist us with providing, promoting and managing our products and services). These may include our IT service providers and third party storage providers, marketing and communications providers, data analysis organisations, and professional advisors and consultants (e.g. legal, insurance and financial advisors); and
- government and law enforcement agencies (including regulatory bodies) to comply with our legislative or regulator obligations (such as to assist with police investigations).
- In some instances, for those who have agreed to share their personal story with TTN, this information may be shared on the TTN website or social media accounts.

## **DO WE SHARE YOUR PERSONAL INFORMATION OVERSEAS?**

We generally only collect and store personal information in Australia. However we may share some personal information with our external service providers located overseas (for example, we use service providers located in the United States of America to provide services to us in connection with email).

We only ever share your personal information outside Australia where we are permitted to do so under the Privacy Act. Generally this means we will take reasonable steps to ensure your personal information is treated securely and in accordance with the requirements of the Privacy Act.

There are other circumstances where we may share your personal information to an overseas recipient. For example, where you have provided your consent or we are otherwise permitted to do so under the Privacy Act or other relevant laws.

## **DO WE USE OR SHARE YOUR PERSONAL INFORMATION FOR DIRECT MARKETING?**

When you provide your personal information to us, we may use that personal information to send you direct marketing communications to keep you informed about products and services offered by TTN (including any new content we have recently published) and carefully selected partners which we think might be of interest to you based on your interactions with us.

We may communicate with you (and send these electronic messages and tailored advertising) through various channels, such as via regular mail, email or SMS.

We will only send these communications in accordance with applicable privacy and marketing laws, and only where you have not opted out from receiving such communications from us.

You are always in control of the direct marketing communications which you receive and can opt-out at any time. Generally you can opt-out by following the relevant opt-out or unsubscribe instructions in the relevant communication (such as email or SMS message).

You can also contact us using our contact details set out below to tell us you would like to stop receiving direct marketing communications from us.

Importantly, regardless of whether you opt out from receiving any or all direct marketing communications, we will still communicate with you if we are required by law to provide you with information, or in relation to the services or products we are providing you with (for example, in relation to any donations you make).

## **HOW DOES TTN INTERACT WITH YOU VIA THE INTERNET?**

You may visit our website without identifying yourself. If you identify yourself (for example, by providing your contact details when subscribing to our newsletter), any personal information you provide to TTN will be managed in accordance with this Privacy Policy.

When you use our website or receive communications from us, links to websites which belong to other third parties may be included (and are provided for your convenience). You should make your own enquiries as to the privacy policies of these third parties. We are not responsible for information on, or the privacy practices of, any third party websites.

In addition, when you make online payments using our website, we do not collect your credit card or banking details. This is because online payments are handled by third parties ([Keela](#)) – please use these links to see details of their privacy and security policies before making online payments.

## **HOW DO WE STORE AND PROTECT YOUR PERSONAL INFORMATION?**

We are committed to protecting your personal information, and ensuring that we securely store any personal information we collect. We will generally only hold your personal information in electronic form.

We take all reasonable steps to ensure that any personal information we collect, use or disclose is accurate, complete, up-to-date and stored in a secure environment protected from misuse, interference and loss, and from unauthorised access, modification or disclosure.

We store electronic records in secure databases, using trusted third party storage providers based in Australia. We also maintain physical security measures in relation to storage of our electronic records (such as through locks and security systems at our electronic data stores). Using technical methods, we also 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 systems.

Our websites use encryption or other technologies to ensure that your personal information is securely transmitted via the internet (including to protect any payments you make). We encourage you to exercise care when sending your personal information via the internet (for example, when communicating with us online, we ask that you do not include your full account or card details).

We will only keep your personal information for as long as is necessary for the purposes set out in this Privacy Policy or as required to comply with any applicable legal obligations. When we no longer require your personal information (subject to and in accordance with any applicable laws), we will take steps to delete, destroy or de-identify that information.

## HOW CAN YOU ACCESS OR SEEK CORRECTION OF YOUR PERSONAL INFORMATION?

You are entitled to request access to any of your personal information that we have. To make such a request, please contact us using the details set out below.

We will take reasonable steps to ensure that the personal information we collect, use or disclose is accurate, complete and up-to-date. You can help us to do this by letting us know if you notice errors or discrepancies in information we hold about you and informing us of any change in your personal details (for example, if your email address changes).

If you consider any personal information we have about you is inaccurate, out-of-date, incomplete, irrelevant or misleading, you are also entitled to request correction of the information (again, please contact us). After receiving a request from you, we will take reasonable steps to correct your information.

We may decline your request to access or correct your information in certain circumstances in accordance with the applicable privacy laws. If we do refuse your request, we will provide you with a reason for our decision. In addition, if we refuse your request for correction, we will include a statement about your request with the personal information we store.

## HOW CAN YOU MAKE A COMPLAINT ABOUT THE HANDLING OF YOUR PERSONAL INFORMATION?

If you have any questions or concerns please contact us using the details set out below.

Please also contact us in writing if you have a complaint about privacy. If you make a complaint about privacy, the following will occur:

- **Step 1:** We will first consider your complaint to determine whether there are simple or immediate steps which can be taken to resolve the complaint.
- **Step 2:** If your complaint requires more detailed consideration or investigation:
  - we will acknowledge receipt of your complaint within a week and endeavour to complete our investigation into your complaint promptly; and
  - we may ask you to provide further information about your complaint and the outcome you are seeking.
- **Step 3:** We will then typically gather relevant facts, locate and review relevant documents and speak with the individuals involved.
- **Step 4:** In most cases, we will respond to your complaint within 30 business days from when we receive your complaint. If the matter is more complex or our investigation may take longer, we will let you know.

If you are not satisfied with our response to a complaint, or you consider that we may have breached the Privacy Act (including the Australian Privacy Principles), you are entitled to make a complaint to the Office of the Australian Information Commissioner (the Australian privacy regulator).

The Office of the Australian Information Commissioner can be contacted by telephone on 1300 363 992, or you can fill out this [form](#) to make a complaint about our handling of your personal information. Full contact details for the Office of the Australian Information Commissioner can be found online at [www.oaic.gov.au](http://www.oaic.gov.au).

## HOW ARE CHANGES MADE TO THIS PRIVACY POLICY?

We may make changes to this Privacy Policy, with or without notice to you. However, where we make a material change to the Privacy Policy, we will provide notice to you (including by updating our websites, and, where appropriate, notifying you directly). We recommend you visit this Privacy Policy regularly to keep you up to date with any changes we make.

## CONTACT US

You can contact us using the details below:

THE TRANSPLANT NETWORK	
Phone	1300 061 799 You can contact us 9am to 5pm, Monday to Friday AEST
Email	<a href="mailto:privacy@thetransplantnetwork.com.au">privacy@thetransplantnetwork.com.au</a>