

# The **Thalidomide** Trust

## Privacy Notice for Beneficiaries

### 1. Introduction

We are committed to protecting your personal data (any data that can identify you as an individual).

This privacy notice explains how we process (collect, store, use and share) your personal data, and how we look after it. It also tells you about your rights and how to contact us.

This privacy notice is a part of our commitment to complying with our obligations under the UK General Data Protection Regulations (GDPR), and we welcome your feedback to help make it even clearer. We will only process your personal data in the ways described in this privacy notice. This document may be amended from time to time and the latest version can always be found on our website or by contacting the Trust office.

At the Trust, protecting your personal data is very important to us, and we will only use your data as the law allows us to.

### 2. Who are we and how can you contact us?

The Thalidomide Trust Company (the Trust) – registered charity number 266220 - of 1 Eaton Court Road, Colmworth Business Park, Eaton Socon, St Neots, Cambridgeshire, PE19 8ER and [www.thalidomidetrust.org](http://www.thalidomidetrust.org) is the "data controller" for the purposes of data protection legislation. A data controller determines the purposes and means of processing personal data.

The Finance Director is the Data Protection Officer (DPO) for the Trust. The purpose of this role it is to ensure that data protection is an important part of the organisation's culture and working practices. If you have any questions about the use of your personal data, you should contact the Finance Director in the first instance:

By email to [hello@thalidomidetrust.org](mailto:hello@thalidomidetrust.org)

By telephone on 01480 474074

By writing to the Finance Director at the address above

# The Thalidomide Trust

## 3. What personal data do we collect?

The personal information we hold on you as a beneficiary of the Trust might include:

- name and previous name(s)
- date of birth
- email address
- postal address
- telephone number
- photographic images
- local authority
- bank details
- financial information
- carers and care arrangements
- benefits claimed
- lifestyle details
- life insurance arrangements
- communication needs
- vehicles covered by the Trust breakdown cover
- marital status
- details of family members and close contacts, including Power of Attorney
- equipment and adaptations used
- name of GP
- information you have provided through surveys
- Trust website login details
- information disclosed on NAC conflict of interest declarations

We may also hold special categories of personal data such as information about your health and thalidomide damage. We process this special category data only if we are permitted to do so by data protection law, and we have additional measures in place to protect this data when sent out electronically.

If you are also a volunteer, the personal information we hold on you might also include:

- testimonials
- references
- details of DBS (criminal record) checks
- records of training undertaken to perform the role of volunteer.

# The Thalidomide Trust

## 4. How do we use your personal data?

We use your personal data:

- to enable us to keep in touch with you
- to support you as a beneficiary of the Trust
- to enable us to make payments to you
- to enable us to verify your existence easily
- for audit purposes
- for funders of the Trust
- for research (only with your consent)
- to plan and assess services offered by the Trust.

If you complete a contact form on the Trust website this will include your email address and may also include personal information (for example financial information if you make a payment request or health/accessibility needs if you are booking an event). This information is transferred to the relevant member of staff at the Trust to action and is retained in line with the Trust's retention schedule which is part of its Data Protection policy.

## 5. Cookies

Cookies are small text files that are placed on your computer by websites that you visit. They are widely used in order to make websites work, or work more efficiently, as well as to provide information to the owners of the site.

Our website uses cookies to track user activity on the website (for example so we know how many unique visitors we have to the website and which pages are most visited) and to enable various types of functionality. They are never used for advertising purposes.

Details of our cookie policy are provided on the Trust website and all visitors are asked to accept/reject our use of cookies as soon as they access the website.

## 6. What is our lawful basis for processing your personal data?

We are only allowed to process your personal data if we have a lawful basis for doing so.

The legal bases on which we process your data are:

- Where it is necessary to comply with our legal obligations and/or
- Where it is necessary for the legitimate business of the Trust
- Where we have your consent.

# The Thalidomide Trust

---

## **7. How do we keep your personal data secure?**

We maintain a high level of security in relation to the processing of your personal data. This is very important to us, and we take steps to ensure that any data we hold about you is safe.

Information is stored digitally on computer systems with multiple levels of passwords and disk encryption, accessible only to the Trust.

Full information is accessible only to our staff, and for the purposes we mentioned above.

Most documents relating to you are scanned to your individual client record and shredded, however we do occasionally store information about you securely in paper files.

We place great importance on the security of all personally identifiable information associated with our beneficiaries. All personal financial data is encrypted and we have security measures in place to protect against the loss, misuse and alteration or destruction of personal data under our control. Information is stored by us on password protected computers located in the UK.

## **8. How do we communicate with you?**

Whilst some communications at the Trust are essential for beneficiaries to receive (e.g. grant information), there are a number of other communications that you can either 'opt in' or 'opt out' of. You will always have the choice of receiving our communications either via email or post. If you would like to change the way we communicate with you, please contact the Trust office for a new Communications Preference Form or amend your communications preferences on the Trust website.

To enable us to tailor communications to your individual needs, we record your communications preferences on our beneficiary database and use an external bulk-mailing system. To do this, we have to share your email address and salutation with an external supplier so we will always ensure that any companies we use for this purpose are UK GDPR-compliant. This means that if they are outside of the UK, they will have appropriate safeguards.

Whenever we send sensitive information by email to you or to an agreed third party (e.g. a doctor we are making a referral to), we will do so using a password protected attachment or via a secure data-link.

## **9. Who do we share your personal data with?**

We may pass your personal information to:

- anyone you appoint to act on your behalf
- regulatory bodies

# The Thalidomide Trust

---

- our external auditors
- beneficiary volunteers (only with your consent). This includes the Trust's Campaigns Team where you have agreed to share your contact details with them.
- any person/organisation that the Trust contracts or employs to supply services (such as a research company)
- any other person or organisation where you have given consent
- or if the law, public duty or our legitimate interest requires the Trust to do so.

In each case, we are satisfied that they adhere to the UK GDPR, adopting the same high standards for protecting your personal data.

## **10. How long do we keep your personal data for?**

Your data will only be kept for as long as necessary. The period of time that we keep each type of information is set out in the Trust's retention schedule which is part of its Data Protection policy. You can also let us know at any time if information the Trust holds about you has changed so we can update it.

## **11. What are your rights in relation to personal data we process?**

Unless subject to an exemption under the UK GDPR, you have a number of rights with respect to your personal data. You have the right to:

- request a copy of the data we hold about you and details of what we do with that data (known as a subject access request)
- update or amend the data we hold about you if it is wrong
- change your communication preferences at any time
- withdraw your consent to use of your personal data where we are relying on consent as the lawful basis for processing it
- ask us to remove your personal data from our records
- ask us to restrict the processing of your personal data
- obtain a digital copy of certain personal data
- raise a concern or complaint about the way in which your data is being used
- ask us to explain any automated processing we carry out and the impact of this on you.

We may ask for reasonable proof of your identity before providing you with data or carrying out any of the above actions.

# The Thalidomide Trust

---

You also have the right to withdraw your consent if you have previously given it but this may limit the ways in which we are able to support you.

## **12. How can I exercise my rights, complain or comment?**

If you wish to exercise your rights, or if you have a question or complaint, in the first instance please contact us at the Trust office, using the information in the 'Who are we and how can you contact us?' section.

If you are not happy with the way we respond, you can always make a complaint to the Information Commissioner's Office (ICO), the UK supervisory authority for data protection issues. You can contact the Information Commissioners Office on 0303 123 1113 or via email <https://ico.org.uk/global/contact-us/email/> or at the Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF.

# The Thalidomide Trust

## DOCUMENT REVISION AND SIGN OFF INFORMATION:

|                                  |                                 |
|----------------------------------|---------------------------------|
| <b>Policy:</b>                   | Beneficiary Privacy Notice      |
| <b>Date Policy Written</b>       | August 2015                     |
| <b>Last Reviewed and Updated</b> | March 2023                      |
| <b>Reviewed by</b>               | Suzanne Lluch, Finance Director |
| <b>For next regular review:</b>  | March 2024                      |