



Trigeminal Neuralgia Association UK

Registered Charity No. 1155001

Data Protection Policy

	Name	Position	Signature	Date
<i>Reviewed by:</i>		Chairman		
Next Review date: by April 2017 latest (individual sections to be reviewed on a rolling basis)				

Signed
Chairman

On behalf of the Executive Committee

Dated

Data Protection Policy

Introduction

Many of us in the Trigeminal Neuralgia Association UK (TNA UK) know from personal experience just how important it is to pursue every avenue in an attempt to fully understand the nature of the condition. We need to convey that understanding to the medical professions with appropriate evidence to ensure the need for continuing research into elimination or at least alleviation of the condition.

TNA UK needs to gather and use certain information about individuals as described above in order to achieve any sort of progress. Those involved can include members, employees, volunteers and other people the organisation has a relationship with or may need to contact. Accordingly, we are very aware of the need to ensure that any personal information we hold and process complies with the Data Protection Act (DPA).

Data protection law

The Data Protection Act 1998 describes how organisations - including TNA UK - must collect, handle and store personal information. The DPA is underpinned by eight important principles. These say that personal data must:

1. Be processed fairly and lawfully
2. Be obtained only for specific, lawful purposes
3. Be adequate, relevant and not excessive
4. Be accurate and kept up to date
5. Not be held for any longer than necessary
6. Processed in accordance with the rights of data subjects
7. Be protected in appropriate ways
8. Not be transferred outside the European Economic Area (EEA), unless that country or territory also ensures an adequate level of protection

Responsibilities

Everyone who works for or with TNA UK has some responsibility for ensuring data is collected, stored and handled appropriately. Each person that handles personal data will ensure that it is handled and processed in line with this Policy.

Our Data Protection Officer (DPO) oversees all aspects of this Policy and will ensure that:

- * Privacy is not infringed – see [Privacy Policy](#)
- * Any personal data used in research is done so with anonymity or with an individual's consent.
- * The only people able to access data covered by this Policy are those who need it for their work.
- * Data will not be shared informally.

Data storage

When data is stored on paper, it will be kept in a secure place where unauthorised people cannot see it.

When data is stored electronically, it will be protected from unauthorised access, accidental deletion and malicious hacking attempts.

TNA UK does not store data unnecessarily and all data is regularly reviewed, updated and deleted where required. However, in view of the nature of TN and the current state of research, no particular timescale exists as to how long data will be kept.

Data use

Personal data is of no value to TNA UK unless the charity can make use of it. As TN is a rare condition and, with the current level of medical knowledge and involvement, it follows that TNA UK is a small charity. It relies on an equally small number of dedicated volunteers who use their expertise to help promote the Association and its work.

Accordingly, it may be necessary on occasion for personal data to be electronically held, transmitted or used by a data processing agency or used by a volunteer as part of their work. Under such circumstances all data will be encrypted and any duplicated data will be deleted when the work for which it is being used is complete. The DPO will follow up to ensure compliance with the DPA.

Data accuracy

The law requires TNA UK to take reasonable steps to ensure data is kept accurate and up to date. The more important it is that the personal data is accurate, the greater the effort the Association will put into ensuring its accuracy. It is the responsibility of all employees who work with data to take reasonable steps to ensure it is kept as accurate and up to date as possible.

Subject access requests

All individuals who are the subject of personal data held by TNA UK are entitled to:

- * Ask what information the Association holds about them and why.
- * Ask how to gain access to it.
- * Be informed how it is kept up to date.
- * Be informed how the Association is meeting its data protection obligations.

Individuals will be charged £10 per subject access request and the request should be made in writing, addressed to the Data Protection Officer and sent to:

TNA UK
PO Box 234
Oxted
RH8 8BE

The aim is to provide the relevant data within 14 days and will be posted to the address that is held on record.

Disclosing data for other reasons

In certain circumstances, the DPA allows personal data to be disclosed to law enforcement agencies without the consent of the data subject. Under these circumstances, TNA UK will disclose requested data. However, the DPO will ensure the request is legitimate, seeking assistance from the Trustees and from the Association's legal advisers where necessary.