

# Syncope Trust And Reflex Anoxic Seizures (STARS)

## Information & Privacy Policy

Version 1.0

Effective from May 2018

**Introduction & Description** – This policy defines the legal basis for processing and sharing privileged personal and sensitive information held and processed by Syncope Trust And Reflex Anoxic Seizures charity relating to information stored, processed and shared by Syncope Trust And Reflex Anoxic Seizures regarding all Employees, Donors, Subscribers, and Suppliers.

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## 1. Definitions

For this policy the following definitions apply:

- **STARS** mean the Syncope Trust And Reflex Anoxic Seizures charity, any reference to either within this policy refers to the legally established charity which is registered with the charity commission with reference 1084898.
- **Company Head office** means Unit 6, Essex House, Cromwell Business Park, Chipping Norton, Oxfordshire, OX7 5SR
- **Staff** means direct employees of the STARS Charity.
- **GDPR** means General Data Protection Regulation (GDPR) (EU) 2016/679 is a regulation in EU law on data protection and privacy for all individuals within the European Union.
- **DPA** means Data Protection Act 1998
- **EU** means European Union and current and future member countries including the UK pre/post departure from the union.
- **Data subject** means an individual who is the subject of personal data. In other words, the data subject is the individual whom personal data is about.
- **The Data Controller** is a person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed.
- **Data processor** in relation to personal data, means any person (other than an employee of the data controller) who processes the data on behalf of the data controller.
- **Processing** in relation to information or data means obtaining, recording or holding the information or data or carrying out any operation or set of operations on the information or data.
- **Subscriber** means the individual that has subscribed to the STARS charity for the purpose of receiving information and materials published by STARS
- **Donor** means the individual that has given financial support to the Stars charity.
- **Medical Professional** means an individual of a medical background who's information is processed by the STARS charity.
- **PIA** means Privacy Impact Assessment.
- **Breach** means a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data. This includes breaches that are the result of both accidental and deliberate causes.
- **Individual rights** mean the 8 rights for individuals as set out in the GDPR.
- **Personal Data** means any information relating to an identifiable person who can be directly or indirectly identified in particular by reference to an identifier. As defined by the GDPR.
- **Sanative Personal Data** means the data as defined by Article 9 of the GDPR.

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## **2. Acknowledgments.**

The STARS charity recognises all rights and responsibilities provided for in the DPA and GDPR legislation.

## **3. Privacy Statement**

The STARS charity respects privacy and will only use information shared with us for the specified and lawful purposes as provided for under the GDPR. The STARS charity will use and process your information responsibly and will take all appropriate organisational and technical measures to safeguard your information from accidental or unlawful destruction, loss, alteration, unauthorised disclosure or access.

The STARS charity will not share information for any purpose other than the specific purposes detailed in this policy.

At no time now or in the future will the STARS charity share personal information with any third party for the purpose of marketing, advertising or statistical analysis. Although the STARS charity may share the results of any statistical analysis conducted privately by the STARS charity with relevant medical professionals and relevant medical organisations.

## **4. Mission Statement**

The STARS charity's mission statement is:

To alleviate the effects of and provide support and information on, syncope, PoTS and reflex anoxic seizures, to those in distress as a result of these seizures, whether suffered by themselves or as a member of the family group. to advance the education of the medical profession and the general public on the subject of syncope and reflex anoxic seizures and its implications for the individual and family.

## **5. Data processing**

To achieve the STARS charity's mission statement and in providing services to donors, subscribers, suppliers and staff the following personal information may be processed by the STARS charity:

- Staff personal information
- Supplier personal information
- Medical professional's personal information
- Donor personal information
- Subscriber personal information
- Website visitors

## **6. Privacy Impact Assessments**

The STARS charity has not deemed it necessary to conduct a Privacy Impact Assessments in regard to the processing of any information.

## **7. Staff Personal Information**

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**7.1. Lawful Basis For processing** - where personal information is collected about staff and employees, the STARS charity is defined as the Data Controller and our Lawful Basis for processing personal and sensitive information is the Legal Obligation we have to process your personal information in respect to UK employment law, tax, pensions and payments to you.

**7.2. Data Collected** – The following list is an example of the data that is collected and processed regarding all staff and employees of the STARS charity:

- Name, address, email address and contact telephone numbers
- Emergency contact details – name and telephone
- Date of birth
- National Insurance Number
- Pension information
- Bank account information
- UK right to work documentation and
- Work experience, references and Supervisory information

**7.3. Data Sharing** – within the confines of the lawful basis for processing STARS is required to share the following information:

- Salary and employment information with Her Majesty's Revenue and Customs (HMRC)
- Personal information and your right to work documentation will be shared with the Human Resources Support Provider - Peninsular
- Limited details with the company pension provider Nest Pensions, or your elected pension scheme
- Your personal details will be stored in the accounting system at the company head office.
- Your emergency contact details will only be shared with senior managers and directors only when needed for making emergency contact
- The STARS charity will not share your personal information collected for the purpose of employment

**7.4. Retention** - Staff personal information – will be retained for the duration of employment and for a period of two years thereafter.

## **8. Supplier Personal Information**

**8.1. Lawful Basis For processing** - where personal information is collected about suppliers, the STARS charity is defined as the Data Controller and our Lawful Basis for processing personal information is the performance of a contract between the STARS charity and the supplier. The Stars Charity processes personal information in respect to UK law relating to the provision of goods and services, tax and for the processing of invoices and payments.

**8.2. Data Collected** – The following list is an example of the data that is collected and processed regarding all suppliers of the STARS charity:

- Company name, address, email address and contact telephone numbers
- Company contacts including job role
- VAT number and company registration number
- Bank account information

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**8.3. Data Sharing** – within the confines of the lawful basis for processing the STARS charity is to share the following information:

- Accounting information may be shared with Her Majesty's Revenue and Customs (HMRC) in accordance with normal accounting practice
- Limited information may be shared with a representative of the STARS charity accounting and auditing service only when absolutely necessary

**8.4. Retention** – Supplier information will be retained for the duration of time the supplier is providing goods & services to the STARS charity and then for 5 years thereafter.

## **9. Medical Professionals Information**

**9.1. Lawful Basis For processing** - where personal information is collected about Medical professionals, the STARS charity is defined as the Data Controller and our Lawful Basis for processing personal and sensitive information is our Legitimate Interest. Medical professional's personal information is processed in respect of delivering the STARS charity's mission statement.

**9.2. Data Collected** – The following list is an example of the data that is collected and processed regarding medical professionals:

- Name, address, email address and contact telephone numbers
- Company contacts including job role
- VAT number and company registration number
- Medical qualification, registrations and membership to professional bodies
- Work experience

**9.3. Data Sharing** – within the confines of the lawful basis for processing the STARS charity may share the following information:

- Name, address and contact information may be shared with other relevant medical professionals

**9.4. Retention** – Medical professionals information will be retained indefinitely by the STARS charity, at any time the medical professional can ask to be removed from our database.

## **10. Donor Personal Information**

**10.1. Lawful Basis For processing** - where personal information is collected about Donors, the STARS charity is defined as the Data Controller and our Lawful Basis for processing personal & sensitive information is consent. Donor personal information is processed in respect of delivering the STARS charity's mission statement.

**10.2. Data Collected** – The following list is an example of the data that is collected and processed regarding all donors of the STARS charity:

- Name, address, email address and contact telephone numbers
- Age and gender
- Donation value
- If relevant medical background (where donors are also subscribers)

**10.3. Data Sharing** – the STARS charity will not share any personal information with any 3<sup>rd</sup> party other than the affiliated charities AFA and AA.

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However, the following information will be shared with the STARS charity affiliated charities AFA and AA

- Name, address, email address and contact telephone numbers
- Age and gender
- Donation value
- If relevant medical background (where donors are also subscribers)

**10.4. Retention** - Donor information will be retained for the duration of time that the STARS charity has a valid record of consent. At any time, the donor can ask to be removed from our database.

**10.5. Consent** – Donors will be explicitly asked to consent at the time they make a donation, and they consent and their data being held and that they may be contacted by the STARS charity or its affiliates regarding events and services provided by the STARS charity and its affiliates.

- Consent will be explicit and opt-in only, where consent is asked for and no reply is received it will be recorded that consent was not given and the records will be deleted.
- Consent will be renewed every 5 years.

**10.6. Anonymous Donations** – all donors will be asked to consent to their data being processed by the STARS charity, however, consent is not a prerequisite to making a donation. Where a donor wants to make a donation and does not give consent to processing all data will be immediately destroyed and no records held. This excludes the value of the donation, and the donor will be record as being anonymous.

## **11. Subscriber Personal Information**

**11.1. Lawful Basis For processing** - where personal information is collected about subscribers, the STARS charity is defined as the Data Controller and our Lawful Basis for processing personal & sensitive information is consent. subscriber personal information is processed in respect of delivering the STARS charity's mission statement.

**11.2. Data Collected** – The following list is an example of the data that is requested and processed regarding all subscribers of the STARS charity, none of the data below is mandatory:

- Name, address, email address and contact telephone numbers
- Age and gender
- Donation value
- If relevant medical background (where donors are also subscribers)

**11.3. Data Sharing** – the STARS charity will not share any personal information with any 3<sup>rd</sup> party other than the affiliated charities AFA and AA.

However, the following information will be shared with the STARS charity affiliated charities AFA and AA

- Name, address, email address and contact telephone numbers
- Age and gender
- Donation value
- If relevant medical background (where donors are also subscribers)

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**11.4. Retention** - Subscriber information will be retained for the duration of time that the STARS charity has a valid record of consent. At any time, the subscriber can ask to be removed from our database.

**11.5. Consent** – Subscribers will be explicitly asked to consent at the time they subscribe to the STARS charity’s services, and they consent and their data being held and that they may be contacted by the STARS charity or its affiliates regarding events and services provided by the STARS charity and its affiliates.

- Consent will be explicit and opt-in only, where consent is asked for and no reply is received it will be recorded that consent was not given and the records will be deleted.
- Consent will be renewed every 5 years.

## **12. Transfer of Personal Information Outside the EU**

In accordance with the provisions of the DPA and the GDPR the STARS charity will not transfer any information (personal or sensitive) outside the EU for processing either directly or by a 3<sup>rd</sup> party.

Where data is processed in a 3<sup>rd</sup> party system or service, the STARS charity affirms that these services are fully DPA and GDPR compliant and all information is stored within EU data centres.

Where the data subject resides in a country outside of the EU the STARS will take any steps necessary and as required by the laws applicable in the data subject’s country of residence to processes personal information.

## **13. Information retention**

Personal and sensitive information will only be retained for as long as necessary to fulfil the lawful basis for processing and in accordance with the STARS charity’s retention policy and as detailed in sections 7 to 11 of this policy.

All financial information relating to any transaction will be retained for a minimum of six years to begin the year after the financial year that the transaction was completed. This is in accordance with guidelines set out by the HMRC.

It is important to note that in some circumstance it may not be possible to destroy a limited amount of personal and sensitive information when the relevant retention policy expires. These include backups of electronic documents and email communications that may be securely archived. Deletion of any such material will take place when the opportunity to do so arises.

## **14. Data Access**

Access to all personal and sensitive information processed by the STARS charity will only be granted on a “least privileged” basis only. This means that only people that have a specific need to perform a function vital to the lawful basis for processing will be granted access.

All access to personal or sensitive information processed by the STARS charity is reviewed and audited on a regular basis.

All electronic data is backed up in a secure manner for the purpose of disaster recovery and data loss prevention. Access to information in the backup systems is restricted to all users excluding those persons charged with the support of the IT infrastructure.

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## **15. Website Cookies**

The STARS charity website uses cookies. A cookie is a small file of letters and numbers that is sent to and stored on your computer to allow the collection of standard internet log information and visitor behaviour information in an anonymous form.

The cookies used are 'analytical' cookies. They allow recognition and count the number of visitors to see how visitors move around the site when using it. This helps with improving the way the website works, for example by making sure users are finding what they need easily. Similar information about site usage is also gathered from the web servers log from log files.

The STARS charity does not use cookies or log files to personally identify information about individuals, nor is the information gained from the use of cookies shared with any third party. The STARS charity website advertises the use of cookies on the home page which also provides a link to this privacy policy.

## **16. Data Protection Breaches**

Where the STARS charity is the Data Controller for information and when breach has occurred, an immediate investigation will be conducted, and the breach will be reported to the Information Commissioner within 24 hours.

## **17. Individual Rights**

- 17.1. The right to be informed** – The STARS charity recognises the right to be informed and will provide each data subject a copy of this privacy policy before commencement of the processing of personal information.
- 17.2. The right of access** - The STARS charity recognises the right to access any personal and sensitive information processed by the STARS charity from the Data Subject, or in the case of a Client any lawfully appointed representative of the STARS charity will provide any information requested under the right to access free of charge and within 28 working days of the request.
- 17.3. The right of rectification** - The STARS charity recognises the right to rectify any personal and sensitive information processed by the STARS charity from the Data Subject. the STARS charity will make any required rectification requested under the right to rectification free of charge and within 28 working days of the request.
- 17.4. The right to erasure** - The STARS charity recognises the right to erasure and will consider all requests on a case by case basis, requests may only be denied where significant legal or technical reasoning prevents the destruction of records. All requests will be responded to within 28 working days. Where records are not deleted the right to restrict processing will automatically be considered as an alternative.
- 17.5. The right to restrict** - The STARS charity recognises the right to restrict the processing of personal and sensitive information and will consider all requests on a case by case basis, requests may only be denied where significant legal or technical reasoning prevents the destruction of records. All requests will be responded to within 28 working days.



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**17.6. The right to portability** - The STARS charity recognises the right to portability and will cooperate with the relevant Data Controller as required.

**17.7. The right to object** - The STARS charity recognises the right to object, however, in some circumstances this right does not apply to some of the STARS charity lawful basis for processing personal and sensitive information. All requests will be responded to within 28 working days, and where applicable data all processing will cease and the data will be destroyed.

**17.8. Rights in relation to automated decision making and profiling** - The STARS charity does not conduct any profiling and does not rely on any automated decision-making process.

## **18. Accountability and Governance**

**18.1.** The STARS charity has implemented the following Data Protection Policy's:

- The STARS charity Privacy Policy
- The STARS charity Data Security Policy
- The STARS charity Backup and Disaster Recovery Policy

**18.2.** All policies relating to the processing of personal and sensitive information will be reviewed on an annual basis.

## **19. 3<sup>rd</sup> Party Services Used by The STARS charity**

Here are links to the privacy policies of the 3<sup>rd</sup> party services used by The STARS charity:

- Sage Pay Role  
<https://www.sage.co.uk/uk/hrpayrollhero/privacy-policy>
- Microsoft Office 365  
<https://products.office.com/en-gb/business/office-365-trust-center-privacy>
- Peninsular  
<https://www.peninsulagrouplimited.com/privacypolicy/>

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## **20. Policy Review and Version Control**

**20.1.** This policy is reviewed annually and updated accordingly.

**20.2.** Version Control – the table below details the history of updates to this policy.

<b>Date</b>	<b>Description of changes/updates</b>	<b>Version</b>
May 2018	New policy release	1.0