

# Swindon Down's Syndrome Group

## Data Protection & Privacy Policy

Our Data Protection and Privacy Policy explains in detail the types of personal data we may collect about you when you interact with us. It also explains how and why we use it, who we disclose it to, and how we protect your privacy. This policy applies to anyone required to process information on or behalf of the Swindon Down's Syndrome Group.

It's likely that we'll update this policy from time to time, to take account of changes in working practice or the law. We'll notify you of any significant changes, but it's always available on our website should you wish to view it.

### Who we are

The Swindon Down's Syndrome Group, hereby known as SDSG, is a UK registered charity, supporting people with Down's syndrome, and their families in the local community.

### Principles

Swindon Down's Syndrome Group, hereby known as SDSG, needs to collect, keep, maintain and use certain personal information on its current, past and prospective, volunteers, trustees, members and other individuals with whom it has dealings, to carry out its day-to-day operations, to meet its objectives and to comply with legal obligations.

We are committed to processing data in accordance with our responsibilities under the GDPR (General Data Protection Regulation). Article 5 of the GDPR requires that personal data shall be:

processed lawfully, fairly and in a transparent manner in relation to individuals;

collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall not be considered to be incompatible with the initial purposes;

adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed;

accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay;

kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; personal data may be stored for longer periods insofar as the personal data will be processed solely for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes subject to implementation of the appropriate technical and organisational measures required by the GDPR in order to safeguard the rights and freedoms of individuals; and

processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures.”

## General provisions

This policy applies to all personal data processed by Swindon Down’s Syndrome Group.

The Data Protection Officer shall take responsibility for the Swindon Down’s Syndrome Group ongoing compliance with this policy. This policy shall be reviewed at least annually.

We are registered with the Information Commissioner’s Office as an organisation that processes personal data.

The definition of ‘processing’ is obtaining, using, holding, amending, disclosing, destroying and deleting personal data. This includes paper based personal data as well as that kept on computer.

The Personal Data Guardianship Code suggests five key principles of good data governance on which best practice is based. The organisation will seek to abide by this code in relation to all the personal data it processes, i.e.

**Accountability:** those handling personal data follow publicised data principles to help gain public trust and safeguard personal data.

**Visibility:** Data subjects should have access to the information about themselves that an organisation holds. This includes the right to have incorrect personal data corrected and to know who has had access to this data.

**Consent:** The collection and use of personal data must be fair and lawful and in accordance with the DPA's eight data protection principles. Personal data should only be used for the purposes agreed by the data subject. If personal data is to be shared with a third party or used for another purpose, the data subject's consent should be explicitly obtained.

**Access:** Everyone should have the right to know the roles and groups of people within an organisation who have access to their personal data and who has used this data.

**Stewardship:** Those collecting personal data have a duty of care to protect this data throughout the data life span.

## What personal data we collect

Your personal data (any information which identifies you, or which can be identified as relating to you personally for example, name, address, phone number, email address) will be collected and used by us. We'll only collect the personal data that we need.

We collect personal data in connection with specific activities such as membership, registering for an event, trips and outings, parties, donations and volunteering.

You can give us your personal data by completing our membership forms or by corresponding with us (by phone, email or social media).

This personal data you give us may include name, title, address, date of birth, age, email address, telephone numbers, personal description, photographs, medical conditions, and ethnicity).

## Explaining the legal bases we rely on

The law on data protection sets out a number of different reasons for which a not-for-profit organisation, like us, may collect and process your personal data, including:

### **Consent**

In specific situations, we can collect and process your data with your consent. For example, when you complete a membership form.

### **Contractual obligations**

In certain circumstances, we need your personal data to comply with our contractual or legal obligations. For example, if you to attend a trip with us, we will collect your address details in order to send you your information/tickets.

### **Legal compliance**

If the law requires us to, we may need to collect and process your data. We may also have to pass data to regulatory or governing bodies.

### **Legitimate interest**

In specific situations, we require your data to pursue our legitimate interests in a way which might reasonably be expected as part of running our charity and which does not materially impact your rights, freedom or interests.

For example, we will use your address details to send you marketing information by post, telling you about future trips, activities or services that we think might interest you.

## Lawful, fair and transparent processing

To ensure our processing of data is lawful, fair and transparent, SDSG shall maintain a Register of Systems. Register of Systems means a register of all systems or contexts in which personal data is processed by us. The register shall be reviewed at least annually.

Individuals have the right to access their personal data and any such requests made to SDSG shall be dealt with in a timely manner.

We ensure that if we hold information about you, you are able to exercise your rights under the DPA, including the right to be informed that processing is taking place, the right of access to your own personal information, the right to prevent processing in certain circumstances and the right to correct, rectify, block or erase incorrect information.

## Data minimisation

We shall ensure that personal data are adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed.

Observe fully all conditions regarding the fair collection and use of personal information and meet our legal obligations to specify the purpose for which information is used.

## Accuracy

SDSG shall take reasonable steps to ensure personal data is accurate. Where

necessary for the lawful basis on which data is processed, steps shall be put in place to ensure that personal data is kept up to date. Each year we will ask our members to renew their membership and update their personal information.

## Special Category Data

When we provide our services to you we may collect information that could reveal racial or ethnic origin or details of physical or mental health (including SEND). This information is considered “sensitive personal data” under GDPR and other data protection laws.

We only collect this information where it is necessary to deliver our services to you. For example, if you inform us about specific dietary requirements, this could indicate specific religious beliefs. If you provide medical information about yourself, this could reveal information about health.

By providing any sensitive personal data you explicitly agree that we may collect and use it in order to provide our services and in accordance with this Privacy Policy.

If you do not allow us to process any sensitive personal data, this may mean we are unable to allow you to take part in the activities or services we provide.

In addition, we may also share your personal data with our service providers who run or operate the activity or service on our behalf. For example, if you take part in Salamander Fire Course we will provide them with your information to ensure you can safely participate in the activity.

## Archiving / removal

To ensure that personal data is kept for no longer than necessary, SDSG has an archiving policy for each area in which personal data is processed and review this process annually. The archiving policy states what data should/must be retained, for how long, and why.

### **How long will we keep your personal data?**

Whenever we collect or process your personal data, we'll only keep it for as long as necessary for the purpose which it was collected. At the end of that period your data will either be deleted or anonymised, for example by aggregation with other data – so it can be used in a non-identifiable way for statistical analysis or planning.

## Notification

The need we have for processing personal data are recorded on the public register maintained by the Information Commissioner. We notify and renew our notification on an annual basis as the law requires. If there are any interim changes, these will be notified to the Information Commissioner within 28 days.

The name of the Data Controller within our organisation as specified in our notification to the Information Commissioner is Cailey Whitcher (Secretary).

## Responsibilities

Under the Data Protection Guardianship Code, overall responsibility for personal data in a not-for-profit organisation rests with the governing body. In the case of Swindon Down's Syndrome Group, this is the board of Trustees.

The governing body delegates tasks to the Data Controller. The Data Controller is responsible for:

- understanding and communicating obligations under the Act
- producing clear and effective procedures
- notifying and annually renewing notification to the Information Commissioner, plus notifying of any relevant interim changes

All trustees who process personal information must ensure they not only understand but also act in line with this policy and the data protection principles.

It is the responsibility of the Secretary to ensure that personal information provided to SDSG is accurate and up to date. To this end members are required to inform the Secretary or Chair immediately when changes occur, including, for example current address and contact telephone numbers or e-mail.

It is the responsibility of the board of Trustees to ensure that the collection, maintenance and processing of personal information about other volunteers, members, and any other individuals with whom the SDSG has dealings, follows the SDSG's rules on good data protection practice, including:

- only accessing personal data in accordance with legitimate business needs
- adhering to correct retention period guidelines
- disposing of data confidentially
- not making personal data available to unauthorised persons, internally or externally
- ensuring the secure and confidential storage of personal data, electronic and manual records

## Access to information

Anyone who is the subject of personal information held by the SDSG has the right to make a subject access request.

**We respect your right to control your data. Your rights include:**

**Right of access** - you have the right to access and obtain a copy of the personal data that we hold about you.

**Right to rectification** - you have the right to request that we correct any inaccuracies in the personal data stored about you.

**Right to erasure** - in certain circumstances, you have the right to request that we erase your personal data. For example, you may exercise this right in the following circumstances:

- your personal data are no longer necessary in relation to the purposes for which they were collected or otherwise processed by us
- where you withdraw consent and no other legal ground permits the processing
- where you object to the processing and there are no overriding legitimate grounds for the processing
- your personal data have been unlawfully processed
- your personal data must be erased for compliance with a legal obligation

Where we store your personal data for statistical purposes, we may not be able to comply with such a request where it would likely impair such statistical purposes or where we require your personal data for compliance with a legal obligation or in connection with legal proceedings.

**Right to restriction** - you have the right to restrict our processing of your personal data where any of the following circumstances apply:

where you feel that the personal data which we hold about you are not accurate. This restriction will be in place for a period to enable us to verify the accuracy of your personal data

where the processing is unlawful and you do not want your personal data be erased and request the restriction of its use instead

where we no longer need to process your personal data (e.g. any of the purposes outlined above have been completed or expire), but we require it in connection with legal proceedings

where you have objected to our processing of your personal data pending the verification of whether or not our legitimate business interests override your interests, rights and freedoms.

Where you exercise your right to restrict our processing of your personal data, we will only continue to process it with your consent or in connection with legal proceedings or for the protection of the rights of other people or for reasons of important public interest.

**Right to data portability** - you have a right to receive and transfer the personal data that you provide to us in a structured, commonly used and machine-readable format where we process your personal data on the legal bases of: a) your consent; or b) where it is necessary to perform our contract with you. Where you make such a request, we will directly transfer your personal data on your behalf to another controller of your choice (where it is feasible for us to do so).

**Right to withdraw consent** - you have a right to withdraw your consent, at any time, to our processing of your personal data which is based on your consent. Where you exercise this right, our processing of your personal data prior to your withdrawal of consent will remain valid.

**Right to object to processing** - In certain circumstances, you have a right to object to our processing of your personal data where we process it on the legal bases of our legitimate business interest or your consent to marketing. We may not be able to comply with such a request where we can demonstrate that there are compelling legitimate grounds for us to process your personal data which override your interests, rights and freedoms or where the processing of your personal data is required for compliance with a legal obligation or in connection with legal proceedings.

If you would like to make a personal data access request, please email the Secretary at [secretary@swindondownsgroup.org.uk](mailto:secretary@swindondownsgroup.org.uk) with the subject title 'Data request' including the following required information:

- your full name
- a description of your data access request

We will deal promptly with subject access requests and will normally respond within 30 days. If there is a reason for delay, the person making the request will be informed accordingly.

# Security

SDSG take appropriate technical and security measures to safeguard personal information. The following measures will be taken:

- Password protection on personal information files
- Setting up computer systems to allow restricted access to certain areas
- Not allowing personal data to be taken off site (as hard copy, on laptop or on memory stick)

Password protected attachments for sensitive personal information sent by email  
Ensure that personal information is not transferred outside the EEA without suitable safeguards.

## Breach of the policy

The trustees are accountable for compliance of this policy. A trustee could be personally liable for any penalty arising from a breach that they have made. The list of rules is not exhaustive and the SDSG may add to it from time to time or may treat any other actions or conduct as constituting a breach of the spirit of this policy.

Members who consider that there has been any breach of this policy should raise the matter with the trustees.

In the event of a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data, the Swindon Down's Syndrome Group shall promptly assess the risk to people's rights and freedoms and if appropriate report this breach to the ICO ([more information on the ICO website](#)).

Any unauthorised disclosure made by a volunteer may result in the termination of the volunteering agreement.

--END OF POLICY--