

THE NATIONAL DOWN SYNDROME POLICY GROUP

Privacy Policy

The National Down Syndrome Policy Group is committed to a policy of protecting the rights and privacy of individuals in accordance with the General Data Protection Regulation (GDPR) which became law in May 2018.

Data protection principles

The National Down Syndrome Policy Group is committed to processing data in accordance with its responsibilities under the GDPR.

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.”

The National Down Syndrome Policy Group is committed to protecting your privacy. We are dedicated to ensuring all information you give to us is held securely and is only used in a manner that you have consented to or would expect.

How we collect personal information about you?

We may collect personal information from you when you interact with the Down Syndrome Policy Group. There are many occasions when this could happen, for example: if you enquire about our group, register with us, make a donation to us, or otherwise provide us with personal information. We collect data from you when you interact with us online, face to face, by post, over the phone or via SMS.

What information do we collect?

The personal data we collect may include your name, address, telephone number, email address, occupation, areas of special interest or expertise, family details, whether you or family member has Down Syndrome and sometimes bank details if you are making a donation. We will only collect data which is relevant to the purpose for which you have given it.

Collecting specific, minimal and relevant special category data will enable the National Down Syndrome Policy Group to provide appropriate resources and information. This will enable the National Down Syndrome Policy Group to process data to ensure support for all those with Down syndrome and their families, to raise awareness of the condition and to promote equality of opportunity and treatment. The National Down Syndrome Policy Group will sometimes ask for your consent to collect, store and process special category data regarding race or ethnic origin, political opinions, genetic data and data concerning health your health. You can refuse or withdraw consent at anytime and still be a member of the National Down Syndrome Policy Group and participate as fully as your consent allows. If you withdraw your consent, all special category data we have collected from you will be deleted from our records. You can request their special category data be deleted from their records by contacting the Data Officer Lucienne Cooper at lucienne@dspg.uk

We also gather general information about the use of our websites, such as which pages users visit most often and which services, events or facilities are of most interest. We may also track which pages users visit when they click on links in the National Down Syndrome Policy Group's emails. We may use this information to personalise the way our website is presented when users visit it, to make improvements to our website and to ensure we provide the best service for users.

How will we contact you?

We may contact you via post, email, telephone or SMS text. However, we will only contact you by the channel you have told us you wish to receive communications by and where we have received your consent to do so.

As a new member, we will aim to capture your consent for Direct Marketing purposes. We will consider consent to remain valid while you are financially supporting us or receiving our regular communications and have not objected to doing so.

You can give or withdraw consent to Direct Marketing, or change your contact preferences, at any time by emailing us at lucienne@dspg.uk Please let us know if you change your contact details or if you believe any information we hold is incorrect.

Cookies

'Cookie' is a name for a small file, usually of letters and numbers, which is download onto your device, like your computer, mobile phone or table when you visit a website. They let websites recognise your device, so that the sites can work, or work better, and also gather information about how you use the site. A cookie, by itself, can't be used to identify you.

We use cookies to distinguish you from other users of our website. This helps us to provide you with a good experience when you come to our website and also allows us to improve our site. You can opt out of all our cookies (except the strictly necessary ones). Find out how to control and delete cookies in your browser.

How do we use your personal data?

The National Down Syndrome Policy Group shall ensure that personal data is adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed.

The purpose of collecting personal data is:

- to keep you informed about our work if you have requested this or have not opted out of receiving such communications.
- We may also ask you to financially support our work by sending you fundraising appeals.

- We may also use your data to process any donations you have given and any Gift Aid associated with that donation.
- Contact you about public policy matters, or other current events, this could include an invitation to join a petition, letter writing, call or other sort of public policy related campaigns.
- We may also store and share images of our events, activities and news with our members, supporters, in the media and on social media for publicity purposes, to raise the profile of the organisation and Down syndrome, and to help with our fundraising. You will be asked to state what your preferences are, and no images will be shared without your consent.
- Provide or administer activities relating to all our services: updating you with administrative messages, to help us identify you when you contact us, and help us to properly maintain our records
- Improve your experience with us. We may use your information to enhance the service that our team provides, to improve our information and communications, or to personalise the website to better suit your needs
- You can of course ask us at any time to change how we contact you, simply contact lucienne@dspg.uk

How we store your data

We take the security of your personal information extremely seriously. The personal information we collect about you will be used by the officers, organisations and volunteers working on behalf of the National Down Syndrome Policy Group. Officers, organisations and volunteers working on behalf of the National Down Syndrome Policy Group all follow the requirements for collecting, storing and processing personal data as detailed in our GDPR policy.

The National Down Syndrome Policy Group:

- will never sell or share your personal information with organisations so that they can contact you for any marketing activities. Nor will we sell any information about your web browsing activity.
- will only keep your personal information as long as is reasonable and necessary, which may be to fulfil statutory obligations (for example, the collection of Gift Aid).
- will not process your data outside of the National Down Syndrome Policy Group and will not be disclosed to any parties outside of the group.
- may occasionally undertake a process of cleansing data and will delete any information no longer needed to ensure that data we hold is accurate and up to date.
- This information is stored in password protected files or secure online platforms and can only be accessed by the Officers or approved members. Computer security systems are in place to protect internet access from unwanted sources. Any printed information will be locked in a drawer or filing cabinet when not in use and will only be seen by those with permission to do so.

Data security

The National Down Syndrome Policy Group will take all reasonable care to safeguard your personal information through security policies and processes.

In relation to us processing your personal data you have the following rights, which can be exercised at any time.:

- To withdraw your consent for us to process your data.
- To be forgotten – to request your data is no longer processed or quarantined.
- Subject access requests – a right to request a copy of the data we hold about you.
- To object to your data being used by us for the purposes of direct marketing.
- You can also request that we erase any personal data we hold about you.
- The National Down Syndrome Policy Group will regularly review the data it has on individuals and will delete all details when the group ceases to exist.

This does not however include any data we are obliged to keep for administrative, legal, or security purposes

What else you should know about privacy

Our pages may contain links to other websites, and you should be aware that we are not responsible for the privacy practices on other websites.

How to access or update your personal information

You may ask us at any time to update your details, correct or remove information you think is inaccurate by contacting us at lucienne@dspg.uk

Changes to our privacy policy

Our Privacy Policy is reviewed regularly to ensure that it reflects how we use your information. Any changes will be notified to you by updating this policy so please check this Policy to see if any changes have been made that are important to you. Where appropriate, changes will be notified to you by email.

24th March 2021