**Rett UK Privacy Statement – how we use your information**

This privacy statement tells you what to expect when we collect personal information.

**People we collect information on**

We need to collect and use your personal data if you contact us for any reason including if you are a:

* member
* member of our online community
* supporter
* someone who uses our advice and information services
* a visitor to our website
* someone who buys goods from us.
* volunteer
* employee of Rett UK

We have to hold your details to fulfil your enquiry or provide you with the service or membership you have requested.

**Complying with the Data Protection Act and General Data Protection Regulations (GDPR)**

Data Protection principles require Rett UK to process personal data fairly and lawfully. We will offer you choices about the way you are contacted and will be clear about how we will use your information. We will make sure that the reason for collecting information is lawful.

The GDPR says that the information you provide to us about how we process your personal data must be:

* concise, transparent, intelligible and easily accessible;
* written in clear and plain language, particularly if addressed to a child; and
* free of charge.

As required by law Rett UK has informed the Information Commissioner’s Office (ICO) why we collect and process data.

We only hold data about you which is enough for our purpose, nothing more.

We work to make sure the data we hold is accurate and up to date. Accuracy is checked when data is recorded, such as through Royal Mail postcode files.

We only hold personal data as long as necessary. However, we do need to keep personal data from you even if you have requested no further contact. This is so we can make sure we *exclude* you from any activity. For example, trying to recruit new supporters by using a mailing list.

We have systems in place to safeguard your personal data. Access to written and electronic personal data is restricted and has a level of security depending on the sensitivity of the data. No sensitive data linked to a person’s name or address is taken off-site unless it is either password protected or encrypted.

**Marketing communication preferences**

Rett UK aims to make sure that you have an opportunity to opt-out of receiving marketing communications. At any point in time you are able to opt out of hearing from Rett UK. You can decline contact by mail, telephone, SMS or email. You can do this by calling Rett UK on 01582 798 910 or emailing info@rettuk.org.

If at a later date you complete another form, giving different contact preferences, we will use those preferences that you have opted in to.

Every time we contact you in the future we will give you the chance to tell us you don’t want that particular information again. For example, with each raffle ticket appeal, you will have the chance to opt out of receiving future raffle tickets.

**Note on email marketing**

Emails and text messages are also covered by the Privacy and Electronic Communications Regulations. When your email address or mobile telephone number is recorded in a marketing communication, we will offer to include you in any future email / text updates. You will have to tick a box (opt in) to agree to your details being used for marketing emails / texts.

Also, any marketing emails by Rett UK will include the opportunity to unsubscribe from future emails. If you wish to unsubscribe from future texts please email us at info@rettuk.org.

**Giving your data to other organisations**

We use third parties to handle some of our services on our behalf, as allowed under the Data Protection Act.  These organisations are only allowed to use your personal information for the specific purpose they have been contracted for. For example, this could be to send a letter to you or process your direct debit.

We have also stated in our ICO registration that we will not transfer data outside the European Economic Area.

We always transfer your personal data securely – through a secure FTP (File Transfer Protocol) website, or as a password-protected file.

Unlike some organisations, we will not swap or sell your data to another organisation for them to use for marketing purposes.

**Sensitive data**

If you call our helpline we will record:

* your interests in Rett syndrome and what affects you in your daily life, this helps us to monitor the demand for our services and to plan future content of our information booklets, fact sheets and web pages
* your age, relationship/connection to someone with Rett syndrome and ethnicity, this helps us to identify trends in the types of people using our services and plan to improve access to our services

Some of this is classified as “sensitive data” (and is subject to additional Data Protection regulations). We will ask for your explicit consent to record and process sensitive information.

We have legally backed reasons for collecting sensitive data. It helps us to achieve one or more of our charitable aims, such as more targeted membership benefits. None of this data will be used in a way that could harm you as an individual.

**Your data on our website**

If you use any of the email facilities or forms within our sites, we will capture your email address, your name and, where relevant, your postal address. This means we can fulfil your request, enquiry or order. As with off-line data capture, we will ask if you want to opt-out of being contacted in the future by mail, telephone, email or text.

If you use any of the secure forms within the site, your credit card information is only used to complete that transaction. All such forms are secure and cannot be accessed by anyone other than the members of staff necessary to complete the transaction.

Information is automatically provided on your browsing behaviour through the use of [cookies](https://www.epilepsy.org.uk/cookies) on our sites. This information does not enable us to identify you personally, but does allow us to track usage of our sites so that we can keep improving them.

**Children’s data**

We will keep their information related to children in same manner as we do for adults in order to service the parent carer’s membership. If a child uses the helpline or uses any other email facility to contact us, their information will only be used to deal with their enquiry.

We recognise the need to protect the privacy and safety of children under 16. Parental permission will have been obtained to use the image and any text related to the image that could possibly identify the child.

**Accessing information held about you**

Rett UK will assist you if you want to see the information we hold about you, for a £10 administration fee. A request should be made in writing, by letter or by email to info@rettuk.org. In most cases we will reply to a request quickly and certainly within 40 calendar days.

Incorrect data can be changed, blocked or destroyed.

You also have a right to prevent us processing your data for marketing or if it is likely to cause distress.

If you have already requested and received this information, there will need to be a reasonable period of time before you can request the information again.

**Changing your communication preferences**

You can change your communication preferences at any time. You can choose whether we contact you by mail, telephone, email or text message. You can also choose whether or not you receive information on certain activities of Rett UK, such as appeals, campaigns and raffles. Just contact us - either in writing to Rett UK, Victory House, Chobham Street, Luton, LU1 3BS or by email to info@rettuk.org.

**Asking for your data to be deleted**

At all times you can ask Rett UK to stop using your personal data. However, we usually keep the personal data of people who have requested no further contact. This is so we can make sure we *exclude* them from any activity aiming to recruit new supporters.

**The remit of this policy**

This privacy notice does not cover information gathered on other websites outside our control.

**Changes to this privacy statement**

We keep our privacy statement under regular review. Any updates will be posted on our website. Supporters that we are in contact with will be informed if there are major changes.

This privacy policy was last updated on 30th November 2017.

**How to contact us**

Requests for information about our privacy statement can be emailed to info@rettuk.org or by writing to:

Rett UK

Victory House

Chobham Street

Luton

LU1 3BS

For a more detailed list of what information we collect and how it is used you can visit the ICO website https://ico.org.uk/ESDWebPages/DoSearch and view our registry entry: **Registration number: Z273623X.**

You also have the right to make a complaint to the ICO should you have any concerns over how we are contacting you or using your personal information.

https://ico.org.uk/concerns or call their helpline on 0303 123 1113.