

Our Privacy Statement

We are The Aarskog Foundation supporting patients and families whose lives have been affected by this Rare Genetic condition. We are a registered company in Britain and our registered address is Wilton, Breadalbane Street, Tobermory, Isle of Mull, Argyll & Bute.

We are registered with the Information Commissioner's Office as a data controller and our registration number is: ZA245873 .

Within the context of this privacy and cookie policy, 'we', 'us', 'our' or 'TAF' refers to The Aarskog Foundation, so whenever you see these words, we are talking about this organisation.

What is a privacy and cookie policy?

At The Aarskog Foundation, we are committed to keeping the trust and confidence of everyone who comes into contact with us, so it is important that you know we record your personal data when you do things like visit our website or use our services. We want you to trust us with that information. This privacy and cookie policy explains all you need to know about:

- what information we collect
- why we collect it
- what we do with it
- when we may share it with others
- how you can access and update your information

Your Privacy

Everyone has rights with regard to the way in which their personal data is handled. During our activities, we will collect, store and process personal data about our clients, suppliers and other third parties and we recognise that the correct and lawful treatment of this data will maintain confidence in the organisation and will provide for successful business operations.

Your personal data, which may be held on paper or on a computer or other media, is subject to certain legal safeguards specified in the Data Protection Act and equivalent EU regulations.

This policy and any other documents referred to in it, sets out the basis on which we will process any personal data we collect from you or that is provided to us by yourself or other sources. This policy sets out rules on data protection and the legal conditions that must be satisfied when we obtain, handle, process, transfer and store personal data.

Why do we collect your personal data?

Basically, to improve the way we communicate and work with you. The information provided by you to us during your use of the services, or otherwise when using the website, will be held by us on our servers and computers and used by us to review, develop and improve our support services, the website and on-line services and to enable us to provide you with relevant information as requested by you.

So, to summarise: When you use our website or services, you are agreeing for us to store and process your personal data. The ways we do that are explained in this policy – it is a guide for us to follow too, and we take it very seriously.

Lawful basis for processing your personal information

Under Article 6 of the General Data Protection Regulations (GDPR) our lawful basis for processing and holding personal information is 'legitimate interest' as it is necessary for TAF to use this information in order to provide you with our services.

What types of information do we collect?

NON-PERSONAL INFORMATION

This type of information does not tell us who you are, but it does help us to improve our services.

How do we collect this information?

When you visit and look around our website, we record things like your IP (internet protocol) address – the unique number of the device you are using to access our website, which pages you visit (on our website only), when they were visited, and the type of device you were using. This information helps us create a better experience for everyone who uses our website.

Examples of the type of information that can be collected using your IP address include the type and version of your browser, and the location from which you are accessing our site. This helps us improve how our page templates appear and change content to make it relevant to our website visitors.

PERSONAL INFORMATION

This means any information that may be used to identify you, such as your name, telephone number, postal and email addresses, and your bank details if you are supporting us financially.

How do we collect this information?

There are two main ways that we collect this information; directly and indirectly, including use of third parties (this is explained below).

What does 'directly' mean?

We collect information when you do things such as:

- register on our website
- request a service from us
- fundraise on our behalf
- donate to us
- give personal data to us

What does 'indirectly' mean?

We also collect information when you use a third party, such as Just Giving, or sign up to an event for us on a third party website. We only collect this information with your permission and in line with the supplier's privacy policy.

What does 'third party' mean?

This means other organisations whom we collect data from, but only when you have given them permission. You may give these organisations permission at various times, for example when buying something from a mail order catalogue or joining certain membership organisations. The data we receive depends on your agreement with the organisation. We may also receive information from online services you use such as Facebook or Twitter if you have given them permission to share this with us.

Sensitive information

If you make a referral into our service via our website you will be asked to provide us with sensitive information in order to help us to provide you with the best possible support and ensure fair access to our services. We will always ascertain whether you have given consent for the referral and will take extra care of the information, in line with Data Protection Legislation.

How we use your information

Rest assured; our intentions are always good. We collect your information because we need it to help us fulfil your requests, keep in touch with you, and offer you communications that are relevant to you. So, things like:

- providing any information or services you have requested
- processing financial transactions such as donations, entering a paid event or setting up a Direct Debit. This includes processing gift aid with HMRC if relevant
- keeping a record of any communications between us and you, for example, emails and phone calls

- keeping a record of other interactions too, such as requests for leaflets or attending an event
- managing and improving how we communicate with you – how you prefer to be contacted, and what information you want to receive. We might contact you about our campaigns, events, appeals, volunteering, news, information and advice, as well as other ways you can support The Aarskog Foundation if you have opted-in to receive this information
- researching the interests, behaviours, demographics (for example, age, sex, income), and trends of the people who are using our information, and range of services, both support and non-support related. We may ask if you wish to take part in more research, such as surveys or focus groups, but this will be voluntary (your choice)
- getting more information about you from third parties with whom you have already given consent for us to contact, such as a new telephone number or address. This helps us keep our records up to date, ensuring we continue to provide you with a requested service or to send you relevant communications – if you have chosen to receive them
- responding to complaints or queries and looking into any legal claims

Legal reasons for sharing information

We will share personal information with companies, organisations or individuals outside of The Aarskog Foundation if we strongly believe that access, use, storing or sharing of the information is reasonably necessary to:

- meet any relevant law, regulation, legal process or lawful governmental request
- put in force relevant terms of service, including investigation of potential violations
- detect, prevent or otherwise address fraud, security or technical issues
- protect against harm to the rights, property or safety of The Aarskog Foundation Members, the patients and families we support or the public, as required or permitted by law

We know that legal details can be confusing. If any of the above does not make sense, get in touch and we will be happy to clear up any confusion – it is quite important to know what this all means.

How you can access or update your information

The accuracy of your information is important to us. We're working on ways to make it easier for you to review and correct the information that we hold about you. In the meantime, if you change phone number, address or email address, or any of the other information we hold is inaccurate or out of date, please email us at: support@aarskogsyndrome.foundation.co.uk

Subject Access Requests

You have the right to request a copy of the information we hold about you. To get a copy of this, please write to The Aarskog Foundation' Data Protection Controller at this address:

The Aarskog Foundation, Wilton, Breadalbane Street, Tobermory, Isle of Mull
PA75 6PX

If you would rather speak to someone, please call our freephone 0800 001 6623.

We try our best to respond to all enquiries within five working days of receiving them, and will offer a full response to all information access requests within 30 working days.

Complaints

In the first instance, you should contact TAF using our standard complaints procedure.

If you remain unhappy with our use of your personal data, you have the right to complain to the Information Commissioner's Office. We would encourage you to contact us in the first instance so we can attempt to resolve any concerns.

Any questions about the operation of this policy or any concerns that the policy has not been followed should be referred in the first instance to the Data Protection Controller, support@aarskogsyndrome.foundation.co.uk

Updating your preferences and unsubscribing

You are in control of how we contact you, for example by post or email and you can control this by contacting us on The Aarskog Foundation' website. If you want to stop receiving emails, click the 'unsubscribe' link at the bottom of any of our emails. We would rather you didn't miss out, but we respect that it is your decision!

Making changes to your personal information

If your personal details change, please help us to keep this information up-to-date by getting in touch and telling us.

How we store your information

We ensure there are appropriate technical controls in place to protect your personal details, for example our online forms are always encrypted (this prevents other people accessing them) and our network is protected and checked often.

We regularly review who has access to information that we hold to ensure it is only accessible by trained staff, volunteers and contractors.

We regularly review the information that we hold, and delete anything that is no longer required.

Cookies

Cookies are small text files stored on your device when you access most websites on the internet or open certain emails. Among other things, cookies allow a website to recognise your device and remember if you've been to the website before. We use the term cookie to refer to cookies and technologies that perform a similar function to cookies (eg tags, pixels, web beacons, etc). Cookies can be read by the originating website on each subsequent visit and by any other website that recognises the cookie.

We use these to improve our user's experience of our website, temporarily store data and understand the parts of the website that users are visiting.

We use cookies in order to make our website easier to use and, to support the provision of information and functionality to you.

Cookies are also used to help us gather statistics on the use of our website anonymously, as well as to provide us with information about how the website is used so that we can make sure it's kept as up-to-date, relevant and error free as we can.

By using our website you agree to our use of cookies, including setting and reading cookies on your device. You can choose to restrict or block cookies through your browser settings at any time. For more information about how to do this, and about cookies in general, you can visit www.allaboutcookies.org and www.youronlinechoices.eu

Whilst certain cookies may be set as soon as you visit a website, you can remove them using your browser settings - but this may impact the functionality or performance of the website.

Please note that third parties (including, for example, advertising networks and providers of external services like website analysis services) may also use cookies, over which we have no control, although we may receive services from these third parties (including, for example, for targeted advertising purposes and website analytics).

Do you have any questions?

If you have any questions or want to find out more, please email: support@aarskogsyndromefoundation.co.uk