



Alström Syndrome UK

Strength for today, hope for the future

Privacy Policy

Alström Syndrome UK (ASUK) are committed to protecting your personal information, being clear about what we do with it, and ensuring we only use your personal information in accordance with all applicable laws.

We do not want to do anything with your information you wouldn't reasonably expect.

This Privacy Policy explains:

- How we obtain your personal information
- What information we collect
- How we will use that information
- Who we share your information with
- Your choices about the information we hold
- Your active consent

We collect information directly from you in the following ways so we can:

- Coordinate the multi-disciplinary specialised clinics in partnership with the NHS – this will include collecting your contact details, health and wellbeing information, data about when you were first diagnosed and when your symptoms first presented, your ethnicity and if you are involved in research including clinical trials
- Sign you up for one of our events; including family activities and attendance at the ASUK conference
- Offer assistance (e.g. by emailing or phoning), process any donations made and provide some general fundraising guidance and information gathering
- Obtain information about you from a family member or a friend who contacts us on your behalf or if a fundraiser passes on your details to us
- Make a payment into your bank account through BACS, this will include your account number, sort code, full name and bank details

Personal information is any information that can be used to identify you. For example, it can include information such as your name, date of birth, email address, postal address, telephone number and credit/debit card details, as well as information relating to your health or personal circumstances.

Sensitive personal data

Data protection law recognises that certain categories of personal information are more sensitive. This is known as sensitive personal information and covers health information, racial or ethnic origin, religious beliefs or other beliefs of a similar

nature. We would only collect sensitive personal information where there is a clear need to do so, such as to ascertain what services we provide which are relevant to you. Before collecting any sensitive personal information about you we will make it clear to you what information we are collecting and why.

We may use your information in the ways set out below:

- We use your personal data to give you the information, support and services you require
- We use your information to gain a full understanding of your situation, so we can develop and offer you the best possible personalised services
- We use your personal information to claim Gift Aid on your donations
- We use personal data to carry out statistical analysis and research in order to help us to understand how we are performing and how we can improve our services and meet the needs of people that require our help
- With your consent, we may use your information to send you communications about our work and how you can help us to help you. You can let us know if you would prefer not to receive these communications at any time by emailing Catherine.lewis@alstrom.org.uk or telephoning 07970 071675
- We will not sell your details to any third parties
- We may sometimes share your information with trusted NHS service providers with whom we work in partnership to deliver and improve services for people affected by Alström Syndrome

Security systems

When we collect your personal information, we use strict procedures and security features to prevent unauthorised access. We have security systems in place and patch test our systems on a weekly basis to ensure risks are minimised. However, no data transmission over the Internet is 100% secure. As a result, while we try to protect your personal information, ASUK cannot guarantee the security of any information you transmit to us and you do so at your own risk.

Contact

You can request access to any information we hold about you or let us know if you no longer wish to receive communications from us. This is easy to do by contacting Alström Syndrome UK by post at 4 St Kitts Close, Torquay, Devon TQ2 7GD, by email Catherine.lewis@alstrom.org.uk or by telephone 07970 071675. Please let us know of any changes to your personal information or if you have any questions or queries about this policy.

ASUK are committed to protecting your personal information, keeping it safe and being clear about what we do with it.

We will never under any circumstances sell your information.

Please get in touch if you have any queries, full contact information is available at www.alstrom.org.uk