

Albinism Fellowship UK & Ireland
PRIVACY NOTICE FOR OUR MEMBERS

We are committed to respecting your privacy. This notice is to explain how we may use personal information we collect before, during and after your membership with us. This notice applies to you if you have registered to become or are or have been a member of our charity. This notice explains how we comply with the law on data protection, what your rights are and for the purposes of data protection we will be the controller of any of your personal information.

References to **we**, **our** or **us** in this privacy notice are to Albinism Fellowship UK & Ireland.

We have not appointed a Data Protection Officer to oversee our compliance with data protection laws as we are not required to do so, but our Trustee Board has overall responsibility for data protection compliance in our organisation. Contact details are set out in the "Contacting us" section at the end of this privacy notice.

1. PERSONAL INFORMATION WE MAY COLLECT FROM YOU

When you apply to be a member, you may initially provide us with or we may obtain **personal information** about you, such as information regarding your:

- o personal contact details that allows us to contact you directly such as name, title, email addresses, postal address and telephone numbers;
- o date of birth;
- o gender;
- o membership start and end date;
- o records of your interactions with us such as telephone conversations, emails and other correspondence
- o any payment details you provide so that we can receive payments from you and details of the financial transactions with you;
- o records of your attendance at any events run by us or in partnership with other organisations

- o family members,

2. SPECIAL CATEGORIES OF PERSONAL INFORMATION

We may also collect, store and use the following "**special categories**" of more sensitive personal information regarding you:

- o information about your race or ethnicity
- o information about your health, including the type of Albinism you or your family member has

In relation to the special category personal data that we do process we do so on the basis that

- o the processing is necessary for reasons of a legitimate interest, on a lawful basis; and
- o based on your explicit consent.

In the table below we refer to these as the "special category reasons for processing of your personal data".

3. WHERE WE COLLECT YOUR INFORMATION

We typically collect personal information about our members when you apply to become a member of the charity, or when you make a query and/or complaint or when you correspond with us by phone, via a web form, e-mail or in some other way.

4. USES MADE OF THE INFORMATION

The table below describes the main purposes for which we process your personal information, the categories of your information involved and our lawful basis for being able to do this.

Purpose	Personal information used	Lawful basis
To administer any membership you have with us and manage our relationship with you, including dealing with payments and any support enquiries made by you	All contact and membership details, transaction and payment information, records of your interactions with us via OS ticket system, email, facebook messenger.	This is necessary to enable us to properly manage and administer your membership with us and to run the Charity.
To send you information which is included within your membership including details about events we organise, and any updates on the Charity in general	Contact and membership details.	This is necessary to enable us to properly manage and administer your membership with us and to help us run the Charity.
To answer your queries or complaints	Contact details and records of your interactions with us via OS ticket system/email/face book messenger	We have a legitimate interest to provide information provision services and complaint handling services to you .
Retention of records	All the personal information we collect.	We have a legitimate interest in retaining records whilst they may be required in relation to complaints or claims. We need to retain records in order to properly administer and manage your membership and run our charity and in some cases we may have legal or regulatory obligations to retain records. We process special category personal data on the basis of the “special category reasons for processing of your personal data” referred to in section 2 above.
The security of our IT systems	Your usage of our IT systems.	We have a legitimate interest to ensure that our IT systems are secure.
To assess event attendance and performance	Records of your attendance at any events hosted by us or by others.	We have a legitimate interest in doing so to ensure that we can assess the success of events and ensure that our charitable funding is properly directed and our events reach the maximum numbers of people with Albinism.
For the purposes of promoting the charity, and our events.	Images in video and/or photographic form.	Where you have given us your explicit consent to do so.

To comply with health and safety requirements	Records of attendance, medical information.	We have a legal obligation and a legitimate interest to provide you and other members of our organisation with a safe environment in which to participate in our events. We process special category personal data on the basis of the “special category reasons for processing of your personal data” referred to in section 2 above.
To administer your attendance at any events you sign up to	All contact and membership details, transaction and payment data.	This is necessary to enable us to register you on to and properly manage and administer your attendance at events we run.
To use statistical information about your albinism /your family member’s albinism to speak with authority with other organisations.	Health, disability and medical information	We process special category personal data on the basis of the “special category reasons for processing of your personal data” referred to in section 2 above.
For the purposes of equal opportunities monitoring	Name, title, date of birth gender, information about your race or ethnicity and health and medical information	We have a legitimate interest to promote a charity that is inclusive, fair and accessible to all. We process special category personal data on the basis of the “special category reasons for processing of your personal data” referred to in section 2 above.

For some of your personal information you will have a legal, contractual or other requirement or obligation for you to provide us with your personal information. If you do not provide us with the requested personal information we may not be able to admit you as a member or we may not be able to properly perform our agreement with you or comply with our obligations and we may have to terminate your membership. For other personal information you may not be under an obligation to provide it to us, but if you do not provide it then we may not be able to properly perform our agreement with you.

Where you have given us your consent to use your personal information in a particular manner, you have the right to withdraw this consent at any time, which you may do by contacting us as described in the "Contacting us" section below.

Please note however that the withdrawal of your consent will not affect any use of the data made before you withdrew your consent and we may still be entitled to hold and process the relevant personal information to the extent that we are entitled to do so on bases other than your consent. Withdrawing consent may also have the same effects as not providing the information in the first place, for example we may no longer be able to provide certain member benefits to you.

5. DISCLOSURE OF YOUR PERSONAL INFORMATION

We share personal information with the following parties:

- o Any party approved by you.

- **Venues or event organisers:** where needed to enable us to book accommodation or entry to an event, so that you can participate in the Charity's events
- **The Government or our regulators:** where we are required to do so by law or to assist with their investigations or initiatives.
- **Police, law enforcement and security services:** to assist with the investigation and prevention of crime.

6. TRANSFERRING YOUR PERSONAL INFORMATION INTERNATIONALLY

The personal information we collect is not transferred to and stored in countries outside of the UK and the European Union.

7. HOW LONG DO WE KEEP PERSONAL INFORMATION FOR?

The duration for which we retain your personal information will differ depending on the type of information and the reason why we collected it from you. However, in some cases personal information may be retained on a long-term basis: for example, personal information that we need to retain for legal purposes will normally be retained in accordance with usual commercial practice and regulatory requirements. Generally, where there is no legal requirement we retain all physical and electronic records for a period of 2 years after your last contact with us or the end of your membership. Exceptions to this rule are:

- Details regarding membership queries where we hold records for a period of not more than 12 months;
- Information that may be relevant to personal injury or discrimination claims may be retained until the limitation period for those types of claims has expired. For personal injury or discrimination claims this can be an extended period as the limitation period might not start to run until a long time after the event.

It is important to ensure that the personal information we hold about you is accurate and up-to-date, and you should let us know if anything changes, for example if you change your phone number or email address. You can contact us by using the details set out in the "**Contacting us**" section below.

8. YOUR RIGHTS IN RELATION TO PERSONAL INFORMATION

You have the following rights in relation to your personal information:

- the right to be informed about how your personal information is being used;
- the right to access the personal information we hold about you;
- the right to request the correction of inaccurate personal information we hold about you;
- the right to request the erasure of your personal information in certain limited circumstances;
- the right to restrict processing of your personal information where certain requirements are met;
- the right to object to the processing of your personal information; and
- the right to request that we transfer elements of your data either to you or another service provider

You should note that some of these rights, for example the right to require us to transfer your data to another service provider, may not apply as they have specific requirements and exemptions which apply to them and they may not apply to personal information recorded and stored by us.

Whilst this privacy notice sets out a general summary of your legal rights in respect of personal information, this is a very complex area of law. More information about your legal rights can be found on the Information Commissioner's website at <https://ico.org.uk/for-the-public/>.

To exercise any of the above rights, or if you have any questions relating to your rights, please contact us by using the details set out in the "Contacting us" section below.

If you are unhappy with the way we are using your personal information you can also complain to the UK Information Commissioner's Office or your local data protection regulator. We are here to help and encourage you to contact us to resolve your complaint first.

9. CHANGES TO THIS NOTICE

We may update this privacy notice from time to time. When we change this notice in a material way, we will update the version date at the bottom of this page. For significant changes to this notice we will try to give you reasonable notice unless we are prevented from doing so. Where required by law we will seek your consent to changes in the way we use your personal information.

10. CONTACTING US

In the event of any query or complaint in connection with the information we hold about you, please email info@albinism.org.uk or write to us at PO Box 2535, Ifford, IG1 8NG.

Version dated 21 May 2018