

# Retina UK Privacy Policy

V5 May 2026

## About us

Retina UK is a registered charity. It exists to support people living with progressive sight loss caused by inherited retinal dystrophies (IRDs), and funds cutting edge research to ultimately make their challenges a thing of the past.

We take the safety of your personal information very seriously and below we explain how we keep your information safe and secure. Our full contact details can be found at the end of this document.

To allow you to navigate swiftly to the section of interest to you, this policy covers eight distinct areas:

- [Membership, donors, lottery and fundraising](#)
- [Helpline and service delivery](#)
- [Events](#)
- [Volunteers](#)
- [Surveys](#)
- [Recruitment](#)
- [Testimonials and memories](#)
- [Website and marketing](#)
- [Shop sales](#)
- [Security, general processing and your rights](#)

Within this document we make reference to a lawful basis called 'legitimate interests'. This is simply a clause within the data protection legislation that allows us to process your personal information without your consent providing we have a legitimate reason, and that reason is not outweighed by your

fundamental rights and freedoms. You can find out more about this on the [ICO website](#)

## **Membership, donors, lottery and fundraising**

### **Why we need your information**

To support our community and continue to fund cutting-edge research, we need to process personal information. Information captured is used to manage membership records, keep accurate financial records in relation to donations and gifts, and process personal information relating to supporters and volunteers who generously give their time and help run fundraising and information events. Information is also captured to facilitate supporters' involvement in the lottery, events and activities for which they have registered.

We will also maintain a record of any correspondence or enquiries that you make with us.

### **What information do we capture?**

We typically capture your contact details including name, date of birth, address, email address and telephone numbers. If you offer them, your social media name may also be captured. Where donations, playing the lottery or payments are made, for which we are very grateful, full details of the donation is needed; this will include details of the donation including amount and source, bank or card details, if given, and any gift aid declarations that you may give.

You may share other information with us within your enquiry or correspondence, and we may capture details of any accessibility needs you may have. If you are attending an event we will ask if you have any specific food allergies or

preferences. With fundraising events we usually collect name, email address, contact details and details of any proposed activities, as well as clothing size for certain events.

You may also choose to share details of your, or another individual's, eye condition, other medical diagnosis, or personal circumstances which data protection legislation classifies as sensitive.

We do not knowingly send communications to children, but we may have their details on file if a parent or care giver has sought information from us.

## **The legal reason for processing your information and how long we keep it**

If you make a one-off or regular donation to us, we are legally obliged to retain tax records; we keep our financial records for 10 years from the last interaction with you.

Where you are a member or supporter, to process your personal information and maintain accurate financial records, we rely on your consent, our own legitimate interests or a legal obligation. We retain your records for 10 years from last contact with us.

## **How we obtain your information**

Typically, personal data relating to membership, lottery and fundraising will come directly from you, or your representative. This may be via our phone lines, email, website, social media, lottery site or through one of the numerous online donation sites, such as JustGiving, or where we met you in person at an event.

With your permission, your details may also be passed to us from other not-for-profit and third party organisations.

In relation to corporate supporters and trusts, we may have your details passed to us by colleagues or third parties who believe you may have an interest in supporting us. We may also identify companies and corporate individuals whose details are in the public domain, for example on the Internet, on social media platforms, in a newspaper or magazine.

## **Where your information is stored**

Fundraising and marketing data is held on an online record management system (CRM) held and managed within the UK.

## **With whom we share your information**

Your donor, member and supporter details will be kept within the charity, accessed by staff and from time to time by volunteers. Where required we will share information with the Charities Aid Foundation and HM Revenue and Customs to facilitate financial processes and Gift Aid claims. We may also need to share information with our professional advisors such as our accountants.

When assisting at or attending events we may need to share contact details with venues, organisers and other volunteers.

If you participate in an event, such as the London Marathon, your details will be shared with the event organisers and other third-party organisations who may be assisting us in the running, attendance or management of the event.

## **Helpline and service delivery**

## **Why we need your information**

We provide a range of services to support our community, their relatives and members of the public. These include our Helpline, Talk & Support service, Local Peer Support Groups and Discover Wellbeing.

## **What information do we capture?**

We will capture your contact details including name, address, email address, telephone numbers and, if relevant, your date of birth. If you engage with us via social media, your social media name will also be captured. You may share other information with us including medical details relating to your, or another person's eye condition, other medical diagnosis, or information regarding your personal circumstances. The data protection legislation classifies this type of information, which includes details on race, religion and sexuality as special category or sensitive data.

Telephone calls to our helpline are recorded for training and monitoring purposes.

Photographs, audio recordings of your voice and video are also deemed to be personal data and therefore your personal information will also be held in podcast channels such as Spotify, Regional and local Facebook pages, other social media and on YouTube.

We are required to maintain records of any enquiries you make and keep copies of correspondence between us.

## **The legal reason for processing your information and how long we keep it**

Where information comes directly from you, we are processing your information with your explicit consent, or as a charity we can rely on our legitimate interests to support our members and individuals who have regular contact with us.

If we are concerned about your safety or that of another person, we may process your or their information to protect your or their vital interests. There may also be legal reasons

when we are duty bound to share your personal information with statutory authorities.

Recorded calls will be retained for 30 days and emails to our Helpline, Discover Wellbeing, Talk and Support and Local Groups will be kept for three years unless we believe there is a safeguarding issue. Discover Wellbeing, Talk and Support and Local Groups will be kept for two years. Some recorded calls are kept for longer if they hold significant training value, however we will ensure that they contain no reference to any names, addresses or any information from which an individual can be identified. We acknowledge that there is a small chance that a caller may be identified from their voice alone if they were known to one of our team undergoing training, but as stated under our Security section below, volunteers have signed confidentiality agreements.

Information captured via our website, or our 'contact us' form, is retained on the website for six months.

## **How we obtain your information**

The personal information we hold would normally come directly from you, a relative, friend, or healthcare professional. Your details may also be passed to us, with your consent, from another not-for-profit organisation. If you are on social media, other users may post information about you.

## **Where your information is stored**

With the exception of social media platforms, all of your information is stored within the UK or EEA. We use the Microsoft Office cloud to store information.

## **With whom we share your information**

Your information will be processed within the charity to assist and support you, your information may therefore be shared with trained and authorised volunteers, such as with our Talk and Support service. We use a number of third-party processors, such as our web hosting and email broadcast company to help us process your information, but at all times we remain responsible for the security of your data.

We may need to share your information with our professional advisors, such as our solicitor, or a statutory authority if there is a safeguarding concern. We may share with other not-for-profit organisations who may better support you, but only with your permission.

### **Use of Artificial Intelligence and Safeguarding on Helpline and Talk & Support services.**

When you contact the Retina UK helpline or use our Talk & Support service, we may use assistive technology, including artificial intelligence (AI)-based tools, to help us support your enquiry safely and effectively.

These tools are used to assist our trained staff in identifying potential safeguarding concerns, such as risks of harm to you or others, or situations where additional support may be needed. The technology does not make decisions about your case on its own. All decisions and any follow-up actions are reviewed and taken by our trained staff.

The purpose of using these tools is to help us identify and respond to safeguarding concerns more quickly, ensure that we provide appropriate support and referrals where needed and maintain a safe service for all users of the helpline.

We only use these tools as part of our legitimate interests in providing a safe and effective support service, and where necessary to protect vital interests in safeguarding situations.

Where AI-assisted tools are used, we ensure that appropriate safeguards are in place, including human oversight, staff training, and regular review of system performance.

You have the right to request further information about how automated tools are used in relation to your personal data. Where safeguarding concerns are identified, we may need to continue processing your information to protect your or others' safety.

## **Events**

### **Why we need your information**

We need to collect personal information about delegates and individuals who attend both our virtual and in-person events to manage the event and support individuals with any accessibility needs.

### **What information do we capture?**

For delegates and attendees of our events we record name and contact details, next of kin and where necessary any health, dietary requirements and accessibility needs that they may have. Company and professional details may also be collected if relevant.

We never target children but they may be attending an event and so their details may be processed.

### **The legal reason for processing your information and how long we keep it**

Delegates and attendees' information will be processed with your consent or our legitimate interests to organise the event. Contact data will be held for the duration of the event plus six months. Special category data (e.g. health, dietary requirements etc) will be kept for six months.

## **How we obtain your information**

Your information will typically be collected directly from you, or a representative acting on your behalf.

## **Where your information is stored**

Your data will be stored on our website, Office 365 platform, our CRM system and within our Email and SMS broadcast systems. Our SMS service is located within the UK and our email broadcast provider is currently located in the USA.

## **Virtual Event Platforms**

For our virtual conferences, webinars, and peer support groups, we use Zoom. Zoom processes your information to provide the event platform and stores data in the USA.

## **With whom we share your information**

We will share your information with venues and event organisers, which may include our volunteers, but will only provide the minimum amount of information necessary to fulfil the intended purpose.

## **Volunteers**

### **Why we need your information**

Volunteers generously give their time to Retina UK to enable us to deliver our information and support services, and participate in, and run events; some will have direct contact with vulnerable individuals. We need the personal information of

volunteers to manage and communicate with them and ensure that Retina UK have complied with our fiduciary duties.

We need to collect personal information about volunteers who attend both our virtual and in-person events to manage the event and support individuals with any accessibility needs.

## **What information do we capture?**

For volunteers we record name and full contact details together with social media names and also information regarding their volunteer role and how they support Retina UK. If they chose to share it with us we may also record details of their medical conditions and other personal information relevant to their role. As part of our vetting procedure, we will ask for references and those confidential replies will be held on file, as well as the results of any criminal record (DBS) checks. We will also keep on file a copy of any application form that is completed, details of their volunteering activity and any qualifications or training that has been delivered to them and any correspondence between us. Photographs and videos of events may be taken. If concerns are raised, or complaints received a record of these will be maintained.

## **The legal reason for processing your information and how long we keep it**

Where you choose to work with us as a volunteer we will process your information with your consent. However, when you leave, we may need to retain this information under our legitimate interests or for some other legal reason.

Safeguarding and vetting checks, if performed, will be processed under our legal obligations. We will always ask for permission before recording online events, or taking your photo for promotional purposes. You have the right to withdraw this

consent at any time whereby we will immediately remove your image from any sources over which we have control. However, copies of any recordings or photographs which have been stored by search engines or other third parties may still be accessible. We will keep your information for ten years after our relationship ends.

Delegates and attendees' information will be processed with your consent or our legitimate interests to organise the event.

## **How we obtain your information**

Your information will typically be collected directly from you, or a representative acting on your behalf.

## **Where your information is stored**

Your data will be stored on our Office 365 platform, in our CRM system and within our Email and SMS broadcast systems. All of our systems are hosted within the UK except our email broadcast provider, which is currently located in the USA.

## **With whom we share your information**

We will share your information with venues and event organisers, which may include volunteers, but will only provide the minimum amount of information necessary to fulfil the intended purpose. We may need to share with statutory authorities if we are required to do so by law.

## **Surveys**

### **Why we need your information**

Survey information is needed to allow us to advocate on behalf of our community, to determine the strategic direction of Retina UK, to measure progress and better understand the needs of our community. We ask for certain special category or sensitive

information, such as ethnicity, to allow us to identify if particular communities face specific challenges.

## **What information do we capture?**

Some of our surveys will be anonymous, but where we do ask for personal information, we may capture your name and contact details, details of family history, any medical or genetic conditions, mental health or other concerns, and other information which you care to share with us. On some surveys we may also ask for other sensitive information such as your ethnicity.

Our survey platform will automatically capture your IP address, approximate geographical location and date and time of survey.

## **The legal reason for processing your information and how long we keep it**

We rely on your explicit consent to process your survey responses. We will retain survey information indefinitely, but wherever possible, we will fully or partially anonymise the survey information to protect your privacy.

## **How we obtain your information**

Your personal information will be obtained directly from you, or a representative acting on your behalf via our online survey tool, or through an external market research company.

## **Where your information is stored**

Information will usually be stored on an online survey platform, however, we also use Microsoft and other survey tools to obtain feedback, such as following fundraising events. These platforms are within the UK and EEA.

## **With whom we share your information**

The information you provide to us will be used for our own internal research and advocacy purposes, and we may share anonymised information with academics and other not-for-profit organisations, but we can assure you that where we publish our findings you will not be able to be identified in any way.

## **Recruitment**

### **Why we need your information**

We need to capture your information to manage applications for employment or volunteering. We need to ensure that you are qualified for the position, and we have a duty of care to protect you, our community and other employees and volunteers who work with us.

Your information will help us understand if you have any accessibility requirements and enable us to respect equality, diversity and inclusivity within the organisation.

### **What information do we capture?**

The amount of information we require will depend on our relationship, your job role, and the activities which you intend to assist us with. Basic information such as your name, address, date of birth and contact details are essential, and we may also require details of employment or volunteering history, corporate and personal references, right to work in the UK, and if you are working with vulnerable individuals, it may be necessary to perform a criminal record DBS check. If a DBS search is required, further details will be made available to you. We fully respect the Rehabilitation of Offenders Act.

We may ask for limited sensitive information such as information relating to your health, sexuality, religion and ethnicity but this will be wholly voluntary and only requested after a position has been offered.

## **How we obtain your information**

Most of your personal information will be obtained directly from you, or if you apply for employment via a recruitment agency through that third party. Some information will come from third-party references, and other agencies such as the criminal records bureau.

## **The legal reason for processing your information and how long we keep it**

If you are offered employment, all data processing related to your employment, such as training and personnel records, pay, sickness and disciplinary matters will be processed under legal obligations. Where we monitor the building for security, or our computer networks to ensure no malicious activity is taking place we do so under our legitimate interests to protect the charity and other users. In all other cases where we ask you for information, such as to take your photograph and use it in service delivery, for education or promotional purposes, we would rely on your explicit consent.

For candidates who apply for a position and who are unsuccessful at interview we shall delete their application after one year, and for employees and volunteers, we retain their information for seven years after our relationship ends.

## **Where your information is stored**

All personal and sensitive information is stored on a secure server and is kept to a minimum to reduce the risk of disclosure and unauthorised access. Only master copies are retained and

access to recruitment files are actively managed and regularly reviewed by approved HR personnel.

## **With whom we share your information**

Your information will be held confidentially by our Human Resources Department. It may be necessary to share your information with a manager or volunteer, but you will be made aware should this be necessary.

We have access to external legal and professional advisors and from time-to-time employee and volunteer information may need to be shared with those parties. We also share your information with any statutory bodies such as a court, local authority or police service if we were legally obliged to do so.

## **Testimonials and Memories**

### **Why we need your information**

We collect testimonials and personal memories to help raise awareness of inherited sight loss, share experiences, and inspire others in the Retina UK community. These stories play a crucial role in our campaigns, publications, website, and social media, enabling us to communicate the real-life impact of sight loss and the support available.

### **What information do we capture?**

When you provide a testimonial or share a memory, we may capture your name, contact details (such as email address or phone number), and any personal experiences you choose to share. If you submit photos, audio recordings or videos alongside your testimonial, we will also collect and store these materials with your explicit consent.

### **The legal reason for processing your information and how long we keep it**

We process testimonials and memories based on your explicit

consent. You have full control over how your story is shared, and you can withdraw your consent at any time by contacting us. Unless otherwise requested, we will retain your testimonial or memory for up to five years, after which we may ask for your permission to continue using it. **Please be aware that whilst we may no longer use your testimonial or memories if these have been posted online they will be retained on search engines and other sites for a longer period of time.**

### **How we obtain your information**

We collect testimonials and memories directly from individuals who choose to share their experiences with us. This may happen via our website, email, social media, or in-person at events.

### **Where your information is stored**

Testimonials, associated media, and contact details are stored securely within our internal record management system, hosted in the UK. Any published materials are shared via our website, social media channels, and printed publications, always in accordance with the permissions you have provided.

### **With whom we share your information**

Your story will be shared publicly through our website, newsletters, social media, and printed materials.

### **Website and Marketing**

#### **Why we need your information**

We use information gathered when you visit our website to understand how the site is being used to make it more accessible. We need your information to stay in touch with our existing members and supporters and identify and communicate our message to new supporters.

#### **What information do we capture?**

We capture your contact details including name, address, email address and telephone numbers. If you are attending an event we will capture relevant details about that as well.

Where you have asked us to add you to our [newsletter](#) we will capture your name and email address together with your IP address, your approximate geographical location, such as town or country, and details of any consent you have given. We will also ask how you would like to receive the information.

Our website uses cookies, which are small text files which are transferred to your device to allow our website to operate. Cookies contain anonymous or partly anonymous information which cannot directly identify you. Please see our [full cookie policy](#) for full details.

When we send email newsletters we will record if you open our email and any links that you may click on.

## **The legal reason for processing your information and how long we keep it**

Where you are a supporter, we will rely on your consent or our own legitimate interests to process your information. We will only ever send you marketing emails or SMS if you have given your express permission. We will hold your marketing information and send postal communications, such as with our Look Forward newsletter, and telephone calls under our legitimate interests. Your information will be linked to our donor record and stored for 10 years, but you can ask for the information to be deleted sooner if there is no legal reason why we need to keep it.

Where we are trying to identify new corporate supporters, we will rely on our own legitimate interests to reach out to them.

## **How we obtain your information**

Typically, personal data relating to marketing will come directly from you, and this may be via our website, via social media, through one of the numerous online donation sites, such as JustGiving, or where you attended an event.

With corporate supporters we may have your details passed to us by third parties who believe you may have an interest in supporting us. We may also identify companies and corporate individuals whose details are in the public domain, for example on the internet, on a social media platform, in a newspaper or magazine

Cookies are only ever placed on your system if you visit our website.

## **Where your information is stored**

Marketing data is held in our online record management system, which is hosted in the UK, our email newsletter is broadcast from a third-party platform located in the USA, and our postal items are sent on our behalf by a UK-based mailhouse company.

## **With whom we share your information**

We never share your marketing data with any other company or not-for-profit organisation. We will only share your information with companies who support us in managing your information and staying in touch with you. For example our email broadcast and database companies. We remain responsible for your data whilst in their care.

## **Shop Sales**

## **Why we need your information**

We need your personal information to process your order, collect payment and arrange delivery of the awesome merchandise that you have ordered.

## **What information do we capture?**

We just need details of your name, address and contact details together with items ordered. Credit or debit card information will be required to complete the sale, but this is not held by Retina UK. You may also wish to make a pre, or post sale enquiry and we will maintain records of any correspondence that may occur between us.

## **The legal reason for processing your information and how long we keep it**

We are processing your personal information to fulfil our contractual obligations to you, and deal with any enquiries you may make following the purchase. We shall maintain a record of the order and financial transaction for a period of seven years under a legal obligation.

## **How we obtain your information**

Your information will be captured via our web order form or other manual form when you place your order.

## **Where your information is stored**

Details of your purchases will be stored on our website hosted in the UK and at the checkout you will be passed to our third party payment vendor Stripe, who will be responsible for the security of your financial information. You can read their privacy policy [here](#).

## **With whom we share your information**

We process your orders both internally and externally (dependent on the item ordered). Where external fulfilment companies are used, we will share your data with them to allow them to process your order. Your payment will be processed by a payment processing company called Stripe.

## **Security, general processing and your rights**

### **How we keep your information safe**

We understand that your information is private, and you expect us to keep it confidential. In addition to training all of our team in how to manage your information in confidence, we also have in place technical measures to protect your information. Only those individuals who need to view your information can physically gain access to it.

We keep your information safe by applying a range of technical measures such as using antivirus, firewalls and where possible encrypting personal information. We also ensure that all our staff understand the importance of data protection and confidentiality and we provide training and guidance for them to follow.

We are very careful to ensure that any personal information sent via email is password protected, and where possible we keep all personal data within the UK or European Union where it can be fully protected, however, some of our data processors are located within the USA.

Backups of your information are taken regularly, and we ensure that these are encrypted and password protected. These are stored in the UK.

## **Cookies**

Cookies are small text files that are placed on your device by websites that you visit. They are widely used in order to make websites work, or work more efficiently, as well as to provide information to the owners of the site.

See our full cookie policy [RetinaUK.org.uk/cookie](https://RetinaUK.org.uk/cookie).

## Your rights

When it comes to our personal information, you have several rights which are enshrined in law. We have summarised these rights for you below.

- **Right of access**

you have a right to ask us for a copy of the information we hold about you;

- **Right to be informed**

before we process your personal information we have to give you the opportunity to know what we are doing with the information; that is the purpose of our privacy policy which you are reading now. You also have a right to be informed if there is a serious data breach which may pose a high risk to you.

- **Right to be forgotten**

if there is no legal reason why we are holding your information you can ask us to delete it;

- **Right to object**

if you do not like how or why we are processing your personal information and it is likely to cause, or is causing you harm or distress, you can ask us to stop; this is especially true when it comes to direct marketing, for example when we send you our newsletter;

- **Right to object to automated decision making**

you have a right to ask for any decisions being made about you by automated means, in other words by a computer, to be reviewed by a human being. Be assured, here at Retina UK we do not make any automated decisions about you;

- **Right to have inaccurate or incomplete data rectified**

if you believe that the information we hold on you is factually inaccurate, incomplete, or if somebody reading it would get the wrong impression, you can ask us to correct, or add your comments to it;

- **Right to claim compensation**

if because of how we have used your personal information we have caused any harm or damage, you can apply to the Courts for compensation;

- **Right to withdraw consent**

where we are processing your personal data with your consent, you have a right to withdraw it at any time.

In certain situations, the above rights may not apply, for example if you became an employee you could not ask us to erase all of your information until six years after you left the charity.

## **Accessibility**

We are here to support our service users, and if you have any special accessibility or communication needs, just let us know and we will do everything we can to assist you.

If you are unable to communicate with us yourself, you can ask somebody to act as your representative, however we will need to take additional steps to ensure that they are acting on your behalf.

## **Contact details**

If you have any questions or concerns about how your personal information is being used you can contact us using any of the following channels:

The Data Protection Lead  
Retina UK  
Whiteleaf Business Centre  
11 Little Balmer  
Buckingham  
MK18 1TF

Tel: +44 (0)1280 821334

Email: [Info@RetinaUK.org.uk](mailto:Info@RetinaUK.org.uk)

Retina UK is a registered charity no. 1153851

We are registered with the information Commissioner under registration No. [Z2055543](#).

## **Complaints About How We Use Your Personal Information**

If you have any concerns about how Retina UK collects, uses, stores or shares your personal information, you have the right to make a complaint to us.

We encourage you to contact us first so that we can investigate and try to resolve your concerns promptly.

You can submit a complaint by using the contact details above or by using our online form: [RetinaUK.org.uk/privacy-policy/data-protection-complaints/](https://retinauk.org.uk/privacy-policy/data-protection-complaints/)

We will acknowledge your complaint within 30 days and will respond without undue delay. During our investigation we may contact you for further information and will keep you informed about the progress of your complaint where appropriate.

If you remain dissatisfied with our response, you have the right to complain to the UK Information Commissioner's Office (ICO):

Information Commissioner's Office

Website: <https://ico.org.uk>

Telephone: 0303 123 1113