



## EOS privacy statement for members

**Eczema Outreach Support** is committed to respecting any personal data you share with us, to keep it safe and to not do anything with it that you would not reasonably expect. We only ask for information that allows us to provide services to you or to gather relevant information to campaign for better support for children living with eczema and their families.

EOS is registered with the Information Commissioner's Office under **registration number ZA 131266**

### What we collect and what we use it for

Data gathered	Use of data	Legal basis*
<p><b>About you</b> Your name, address, telephone number and email address.</p>	<p>We use your data to make sure we can contact you and provide a personalised service relevant to you. For example we ask for your address in order to send you a welcome pack in the post and we ask for your phone number so that we can offer you 1-2-1 support over the phone and on occasion send information via text if relevant.</p>	<p>Legitimate interest</p>
<p><b>About your child</b> We ask for your child's name, date of birth and sex.</p> <p>We also ask for any medical details regarding your child's eczema that you are willing to share with us. This</p>	<p>We use this data to be able to facilitate communication with our members and tailor any support to your circumstances, for example so that the materials you receive in your welcome pack are age appropriate for your child.</p> <p>We ask for the medical information in order to tailor our support to your circumstances. For example the issues</p>	<p>Legitimate interest</p> <p>Legitimate interest and Substantial</p>

<p>data is considered special category data under data protection law.</p> <p><b>Please note that this data is about your child, not you – and therefore your child (aged 12 and over) has a right to object to us having this data.</b></p> <p><b>Please see the separate privacy statement for children and young people.</b></p>	<p>faced by a child or young person on immunosuppressants can vary considerably from the issues faced by a child or young person struggling with emollient treatment.</p>	<p>Public Interest - Support for individuals with a particular disability or medical condition</p>
<p><b>Optional information about you</b></p> <p>We may also ask you about any protected characteristics, such as your ethnicity, your sexual orientation or any disabilities. This data is automatically separated from your membership form and stored anonymously. You can choose not to give us this information.</p>	<p>We aim to reach all groups in society and we use this information to produce statistics about the representation of these groups within our membership</p>	<p>This information is anonymous and not personal data</p>
<p><b>About your interactions with us</b></p> <p>We store some data relating to interactions between you and EOS, for example whether a welcome pack has been sent to you, if you have participated in an event or we communicated by email.</p> <p>If we have a phone conversation with you about your child’s situation, we will note in our system that the conversation has taken place along with some summary notes on issues discussed.</p> <p><b>Please remember that some of this data also belongs to your child.</b></p>	<p>Storing this information allows us to tailor our support to our members. It means that we can easily see what support you have received or been offered from us already to avoid any duplication.</p>	<p>Legitimate interest</p>
<p><b>Donation or fundraising information</b></p> <p>If you choose to make a donation to EOS or to fundraise for EOS we will store this information in our records.</p>	<p>This is to make sure we can say thank you to you and so you can receive information relevant to you. Donations and fundraising activities are vital for our work to ensure we have funding available to offer support.</p>	<p>Legitimate interest</p>

	The platforms that we use do not give us any access to your bank or credit card details.	
<p><b>Survey replies</b></p> <p>Survey information is always gathered in anonymous formats. You may have the option to enter your email address in order to take part in a prize draw. The email addresses are always separated from the rest of the data before any analysis takes place and all email addresses are deleted as soon as any prize draw has been completed.</p>	We regularly have surveys in order to help us improve our services and to help us raise awareness of eczema and campaign for better support	Legitimate interest
<p><b>Blog subscriptions</b></p> <p>If you subscribe to blogs from the EOS website or other automated services, then your email address will be held on these contact lists.</p>	<p>This data is not used for any other purpose than what you have subscribed to and is not used in any other context.</p> <p>You can unsubscribe to the blogs at any point.</p>	Legitimate interest
<p><b>Case studies and photos</b></p> <p>If you agree to tell your story or parts of your story we will store this information in our systems</p>	We often ask for case studies and photos in order to help us increase awareness of eczema with healthcare professionals, schools, policy makers and the general public.	Consent

\* We can only use your data if we have a lawful basis to do so.

### Data held by third parties

If you like/follow EOS on any public social media platforms, comment on any EOS posts or join the EOS Facebook group, then this information does not belong to EOS. You should refer to the privacy statement of the relevant platform for further information.

We use Eventbrite to allow members to sign up to EOS events. We delete all attendee lists on Eventbrite within one year of the event.

In some situations we use Mailchimp or other similar platforms for sending out emails. This means that your email address and sometimes also your name (if you receive a personalised email) will be on a list stored in mailchimp. This list will only stay on Mailchimp until confirmation has been received that emails have been sent. After that the list will be deleted.

If you attend an EOS webinar on Zoom this information will be stored on the platform, along with any questions you have asked in the Q&A box. We only keep the information on the platform until we have dealt with any follow ups from a webinar. Any questions from the webinar published later on the EOS website will be kept in an anonymous format.

### **Analytical software**

In some circumstances we may use statistical information from platforms such as Mailchimp to see the level of engagement we have with members and the public.

### **Sharing your data**

In certain situations relevant information might be shared with health care professionals, schools or other statutory services involved in the care of your child, if you agree to it. For example if you have asked for a workshop to be delivered in your child's school we may speak directly to the school about your child's situation and how best to involve your child in the workshop.

EOS might signpost you to other non-statutory organisations, but would only share your details with them if you agree to it.

If you have agreed to tell your story in a case study we may use this information in the press, on our website or social media.

EOS will never share your details for commercial purposes.

EOS will always take action if we have any safeguarding concerns.

Your data is stored in cloud based systems.

### **Retaining your data**

EOS will retain the information provided by you for 3 years after you become an ex-member.

Because of the nature of eczema we know that some families may wish to rejoin EOS within a few years of having left and we therefore hold on to data for a period. The historical data will help EOS provide the best service to you.

You become an ex-member either when your youngest child with eczema turns 18 or you can at any stage request to be removed from the members' list.

After the 3 years EOS will delete all information we hold about you, except for limited statistical information which will be anonymised.

If you chose to still support EOS in some capacity after you are no longer eligible to receive a service we will retain relevant information, for example if you decide to volunteer with us we will retain your contact details.

We may keep your data for longer if we cannot delete it for legal, regulatory or technical reasons.

### **Keeping your data safe**

We regularly review and assess all our safety protocols to keep our systems up to date and secure.

All staff and relevant volunteers undergo training about our security protocols and keeping data safe.

### **Your data and your rights**

You can at any point contact EOS to have your data removed from our systems. If you do so no further services will be provided and EOS will delete all personal identifiable information we hold on you, unless we are unable to for regulatory or legal reasons. To do so, please send the request to [info@eos.org.uk](mailto:info@eos.org.uk) or Eczema Outreach Support, 129 High Street, Linlithgow EH49 7EJ

You have the right to ask for a copy of the information we hold about you, although we may need to charge an administration fee in certain circumstances. To make a request, please send a description of the information you would like a copy of, along with proof of your identity to [info@eos.org.uk](mailto:info@eos.org.uk) or Eczema Outreach Support, 129 High Street, Linlithgow EH49 7EJ. We will supply the information as requested within one month of receipt or advise you if we are unable to comply for any reason.

You also have the right to request rectification and restriction of processing of your personal data, to object to our processing according to your particular circumstances and to request a copy of your data in a suitable format to be provided to another controller. These rights only apply in certain circumstances.