



cystinosis
ireland

Cystinosis Ireland

Website Privacy Policy

Cystinosis Ireland respects your right to privacy and complies with its obligations under the General Data Protection Regulation (GDPR). The goal of this website privacy policy is to help you understand how the Society deals with any personal data you provide when you visit its website or interact with the Society online.

By visiting the Cystinosis Ireland website (www.cystinosis.ie), you are accepting the terms of this website privacy policy.

This website may contain external links to other websites and Cystinosis Ireland is not responsible for the privacy policies of these other websites.

What type of information do we collect?

You may browse our site anonymously but certain functions and pages may be unavailable to you.

We collect information from you when you visit our website, make a donation, sign up to be kept up-to-date, or sign up to get involved with the charity.

When making a donation, registering for a campaign or event, or ordering a product on our website, as appropriate, you may be asked to provide personal details such as name, email address, postal address, phone number or payment information as needed.

What do we use your information for?

Information we collect from you may be used in one of the following ways:

- to provide you with information about the rare disease of cystinosis,
- to provide support services to patients and families of patients living with this disease,
- to promote research into this rare condition, and
- to assist in philanthropic fundraising for research into cystinosis and for cystinosis patient and family support services.

We may also collect and retain your data if you send feedback about any of our activities or make a complaint.

To process donations made on line

Should you decide to donate via our webpage, we will use your information to facilitate this and to follow up with you, where relevant or requested, by email, phone or post on any transactions and issue payment receipts.

To let you know other ways you can get involved in our fundraising and campaigns

From time to time we will use your contact information to let you know how you can get involved in our fundraising and campaigns.

We may also contact you by phone or email if you have given us consent to do so.

We will always respect your privacy and will always give you the option to stop hearing from us.

To communicate Cystinosis Ireland messages to you through other media channels

We may use your information to raise awareness of cystinosis with you via other online channels like Facebook, Google, Twitter, etc., where your information will be kept safe and secure and not shared with any further third parties.

At any time you can request your information not be shared with these channels by sending a request to mail@cystinosis.ie

How do we protect your information?

We use a variety of security measures to securely process and keep your personal information safe when you interact with our website.

We use a secure server so that all supplied sensitive/payment information is transmitted via Secure Socket Layer (SSL) technology and then encrypted into our payment gateway provider's database (Realex Payments). When you make an online transaction, Realex Payments provide us only with the following details: the final 4 digits of your card number, the card type and the expiry date. We do not see or store your full card details when you make an online transaction.

Cystinosis Ireland takes, and will continue to take, all reasonable steps (which includes relevant technical and organisational measures) to guarantee the safety of the data you provide to us and we will only use the data for the intended purpose.

However, the nature of the internet is such that we cannot guarantee or warrant the security of any information you transmit to us via the Internet will be 100% secure.

Do we use cookies?

We value and respect all our website users' privacy and we are committed to safeguarding personal information through compliance with the Data Protection Acts 1988 and 2003 (as amended).

While our website does not make use of cookies, we may collect information regarding what pages are accessed and when, to enable us to understand how our website is used. It is not possible to directly identify individuals from this information.

Do we disclose any information to outside parties?

We do not sell, trade, or otherwise transfer to outside parties your personally identifiable information.

The information you provide when interacting with our website will be kept securely and used only by Cystinosis Ireland in order to make your interaction with us possible.

Your information will not be shared with any other organisation, other than with your permission, or where required by law.

We also reserve the right to enforce our site policies in order to protect our rights and the rights of other individuals in a manner that is safe and compliant with the law.

Non-personally identifiable visitor information may be provided to other parties for marketing, advertising, or other uses. For example, we may disclose the total number of visits to our website.

You control your information

All subscribers to Cystinosis Ireland may make any changes to their information at any time by contacting Cystinosis Ireland at: mail@cystinosis.ie .

Cystinosis Ireland is committed to upholding the rights of individuals and have processes in place for providing individuals' access to their personal information.

A subject access request (SAR) is a request for access to the personal information that Cystinosis Ireland holds about you, which we are required to provide under the General Data Protection Regulation (GDPR) unless an exemption applies.

You can send a subject access request in writing at any time to mail@cystinosis.ie

Where requested, we will provide the following information:

- The purposes of the processing of your personal data;
- What kind of personal data is stored;
- Where this data is stored;
- How long your data is stored.

Your request will be completed in 30 days in an electronic format.

Online privacy policy only

This online privacy policy applies only to information collected through our website and not to information collected offline.

Your consent

By using our website, you consent to our website's privacy policy (this page).

Changes to our privacy policy

We reserve the right to make changes to our web privacy policy at any time without prior consultation; these changes will be posted on this page together with the privacy policy revision date.

Contacting us

If you have any questions regarding this privacy policy, you may contact us using the information below.

Cystinosis Ireland

1-2 Cavendish Row,

Dublin 1

Email: mail@cystinosis.ie

Website: www.cystinosis.ie

CRA No.: 20053796

Date Last Reviewed:

May 23, 2018