

The Renal Association



Data Protection Privacy Notice

Introduction

This page explains why information is collected about you and how your information may be used. This is called a Fair Processing Notice or Privacy Notice. It applies to visitors to the rarerenal.org website who have signed up to the **RareRenal** newsletter and describes how the Rare Diseases Group collects, uses and processes your personal information and how, in doing so, it complies with its legal obligations to the public. Your privacy is important and we are committed to safeguarding your data privacy rights.

This notice will address the following areas:

- Key definitions
- What is RareRenal?
- Why RareRenal collects your information
- What personal information does RareRenal collect?
- Where does RareRenal collect your information from?
- How does RareRenal use your information?
- Who your information is shared with
- RareRenal's lawful basis for collecting your information
- How RareRenal maintains the confidentiality of your information
- RareRenal and partner organisations
- How long your information will be stored
- Your individual rights
- Objections and complaints
- How to contact RareRenal
- Changes to this notice

Key definitions

Data controller – the organisation, person or persons who determine the purposes and means of processing personal data. For the purpose of this notice and how it affects your data the data controller is the Renal Association (the operator of RareRenal).

Data processor – in relation to your personal data, means any person (other than an employee of the data controller) who processes the data on behalf of the data controller.

Data protection officer – an existing employee or externally appointed person in place to assist in monitoring internal compliance, informing and advising on data protection obligations, providing advice regarding Data Protection Impact Assessments (DPIAs) and acting as a contact point for data subjects and the supervisory authority. The contact details for RareRenal's data protection officer can be found at the end of this notice.

What is RareRenal?

RareRenal is a programme to provide up-to-date information on rare kidney diseases for patients, their carers, and their clinicians. It does this through its website, rarerenal.org and a regular newsletter.

RareRenal is operated and governed by the Renal Association, a not for profit organisation registered with the Charity Commission as a membership organisation for healthcare professionals caring for people with kidney disease. Full details of their work can be found here: <https://renal.org/>.

Why RareRenal collects your information

RareRenal collects your information to provide you with information regarding rare kidney diseases and its related work.

What personal information does RareRenal collect?

Newsletter

When subscribing to the RareRenal newsletter, you will be asked to submit your full name (forename and surname) and your email address.

'Contact' page

When submitting a contact request to RareRenal, you will be asked to submit your full name (forename and surname) and your email address.

Cookies

Use of cookies by RareRenal

Cookies are small text files that are placed on your computer 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. Most web browsers allow you some control of most cookies through the browser settings or through free software such as Super-Antispyware or Cleaner. To find out more about cookies, including how to see what cookies have been set and how to manage and delete them, visit the All About Cookies website at <http://www.allaboutcookies.org>

Demographics

RareRenal's webserver records your visits to help RareRenal understand how you use the site, so it can improve the site and provide better services.

Use of links

Throughout RareRenal's web pages, the organisation provides links to other sites which may contain information of interest to site visitors. RareRenal takes no responsibility for, and exercises no control over the organisations, views, or accuracy of the information contained on other servers. Creating a text link from another website to RareRenal's website does not require permission.

Where does RareRenal collect your information from?

Your data is collected through the RareRenal website.

How does RareRenal use your information?

Newsletter

If you agree (consent) to receive communications from RareRenal, your full name and email address will be kept as part of a mailing list for the RareRenal newsletter and for additional updates about RareRenal's work. This is held in a spreadsheet which is stored on a secure server.

Your information is not used for any other purpose.

'Contact' page

When you contact RareRenal via the 'Contact' page on renal.org we will use your contact details to respond to your query or comment. Depending on the nature of the query we may pass on your details to an appropriate individual outside of the Renal Association, but this will only be done with your prior consent to do so.

Who your information is shared with

Your information is not made available to anyone outside of the RareRenal programme team unless you have given prior consent.

The lawful basis for collecting your information

When you enter your personal details into the RareRenal website to sign up to our newsletter, you are asked to consent to receive communications from us. This is the lawful basis under the General Data Protection Regulation for processing your data.

How RareRenal maintains the confidentiality of your information

RareRenal is committed to protecting your privacy and will only use information collected lawfully in accordance with the:

- Data Protection Act (2018)
- General Data Protection Regulation (2018)
- Human Rights Act (1998)
- Common Law Duty of Confidentiality

Think Kidneys will keep your information secure in accordance with its legal responsibilities; including taking reasonable steps to safeguard against your information being accessed unlawfully or maliciously by a third party, accidentally lost, destroyed or damaged.

RareRenal will not disclose your information to third parties without your consent unless there are exceptional circumstances such as situations when the health and safety of others is at risk, or where the law permits information to be passed on.

All Renal Association employees working as part of RareRenal are asked to sign a confidentiality agreement as part of their employment contract. If a sub-contractor acts as a data processor for the UKRR an appropriate contract will be established for the processing of your information.

RareRenal and partner organisations

RareRenal has no partner organisations.

How long your information will be stored

Your data will be stored in the RareRenal database indefinitely for the purposes of sending you information unless you choose to withdraw your consent or ask for your data to be erased. You are able to exercise your rights (as listed below) under Data Protection legislation at any time by contacting RareRenal via the details at the end of this notice.

Your individual rights

This section describes how you can access, amend, erase, and move your personal information, withdraw your consent and object to or complain about the data that we hold about you.

Right to access your data (data subject access requests)

You have the right to receive a copy of your personal information that RareRenal holds by making a written request to the address at the end of this document. RareRenal will normally provide your information within one month of receiving all the information needed from you to respond to your request.

Right to rectification (right to amend your information)

You have the right to have your information amended. Please contact us in writing if you want information corrected.

Right to withdraw consent and have your information erased

You can withdraw consent for RareRenal to hold your data at any time. You can either contact RareRenal directly in writing using the address at the end of this document or reply to the emails that we have sent to you with 'unsubscribe' as the subject.

Right of data portability (right to move your data)

You have the right to request a secure transfer of your data that RareRenal hold about you to another data controller. We will transfer your data to you directly for you to transfer on to the new data controller. You should make the request in writing to RareRenal (see the section 'How to contact RareRenal' for our contact details). No fee will be payable and the information will be transferred within one calendar month.

Right to object

RareRenal use your information for the purpose you consented to. If you do not agree with this you have the right to object. See the section below on 'Objections and complaints' that

explains who to contact if you have an objection. RareRenal will respond to your objection within a month (although may be allowed to extend this period in certain cases).

Objections and complaints

Should you have any concerns about how your information is managed, please contact the data protection officer for the Renal Association in writing (see section below 'How to contact RareRenal'). If you are still unhappy following a review by the data protection officer, you have a right to lodge a complaint with the Information Commissioner:

Information Commissioner
Wycliffe house
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 01625 545745
<https://ico.org.uk/>

How to contact RareRenal

If you have any questions regarding this privacy notice, how your data are used, or wish to exercise your rights, you can contact RareRenal on the details below.

The data protection officer is: Mr Tom Gray

He can be contacted by:

Post:
Tom Gray
RareRenal
c/o The Renal Association
Learning and Research Building
Southmead Hospital
Bristol
BS10 5NB

Tel: 0117 4148 157
Email: tom.gray@renalregistry.nhs.uk

Alternatively, you can contact:

The senior information risk owner – Dr Retha Steenkamp
Email: retha.steenkamp@renalregistry.nhs.uk
Or

The Caldicott Guardian – Dr James Medcalf
Email: james.medcalf@nhs.net

Changes to this notice

We may amend this privacy notice from time to time. If you are dissatisfied with any aspect of our privacy notice, please contact the data protection officer.