

National Registry of Rare Kidney Diseases (RaDaR)

Information sheet for Parents/Guardians.

Thank you for taking a moment to read this information sheet.

What is this research about?

It is often difficult to find out about a rare disease. Doctors may not have diagnosed or treated such a condition before. Clinical research is made more difficult because of this, and sometimes progress in understanding the disease is slow. Patients and families may have difficulty finding out about the illness.

The **National Registry of Rare Kidney Diseases**, also known as **RaDaR**, is an initiative by the kidney specialists in the UK to pull together information from patients who have certain rare kidney diseases. This will allow a much better understanding of how the illness affects people. It will speed up research. If the research leads to benefits, such as better diagnosis, treatments or general advice, the registry is set up to feedback results to patient themselves, or their parents or guardians if they are children.

How does it work?

Your child has a kidney condition that is rare. He/she is therefore invited to participate in the registry. This requires your consent as a parent or guardian. If you agree, clinical information about your child's illness and its history will be uploaded from their hospital and compiled on the RaDaR database. RaDaR will also seek additional information from the NHS hospital episodes statistics database, the NHS prescribing database, the UK Renal Registry, the UK Cancer Registry (if appropriate) and the Office for National Statistics (births/marriages/deaths register). This is in order to obtain a complete clinical picture. From time to time the information will be updated by your Paediatric Nephrologist so that the way in which the illness affects your child is recorded. You will be able to see all the information that is being collected about him or her.

Doctors and scientists already actively researching into the specific disease affecting your child are working together as a group. This is known as the **disease-specific research group**. Once the information about your child is uploaded onto the RaDaR database it will be anonymised. They will then be able to access the clinical information about your child, and others with the same disease who are also on RaDaR. The disease-specific research group may get in touch with you via the Registry either to provide you with updated general information, or to invite your child to participate in research projects.

What would I be agreeing to?

Participating in the registry means that you agree for your child's clinical information to be held on a secure computer system operated by RaDaR. You would be given a secure password that will let you see your child's information via the internet. You would also agree to receive

information from RaDaR and the disease-specific research group from time to time. Your Paediatric Nephrologist will also know that you are participating in the registry, and he or she will be notified automatically if the research group wishes to make contact with you.

RaDaR will not share personal information with any other organization. The registry will let you and your Paediatric Nephrologist know if the disease-specific research group has any information for you. The group will have signed a stringent confidentiality agreement with RaDaR in order that any information can be sent to you. Agreeing to participate in the Registry does not commit your child to engaging in any of the research projects that might be proposed in future by the disease specific research group. Any proposal from the disease-specific research group will have separate approval from a NHS research ethics committee.

Will my child's doctor know about this?

Yes. Your Paediatric Nephrologist knows about the Registry and will discuss it with you. He or she will be responsible for entering the clinical information about your child. He or she will also be provided with feedback from the Registry, and will be notified if the disease specific research group working on your child's condition proposes to make contact with you. Your child's GP will be told that you have agreed to participate in RaDaR.

How secure is my clinical information?

Your child's data will be secure. When the information is submitted it will be encrypted so that personal details cannot be identified. Your child's data will be given a unique identifier, so that when an analysis is undertaken the employees of RaDaR will only know your child's data by that identifier. They will not know your person details. All RaDaR employees are carefully vetted and given security clearance according to their tasks.

A disease specific research group must have signed a strict confidentiality contract with the Registry in order to use it. If they have a research proposal that they wish to bring to your attention, RaDaR will send you the information about it. You would then be able to contact the research group directly if you wish

Can I have time to think about this?

Yes, you can take as much time as you need.

What happens if I change my mind?

You can withdraw from the Registry at any time. You could either write to RaDaR directly or your hospital consultant to make this change. The information concerning your child would then be frozen and there would be no further contact between you and RaDaR or the disease-specific research group.

What happens when my child grows up?

When your child is 16 years of age he or she will be sent a brochure about RaDaR, and you will be sent a copy. It will inform him or her about RaDaR and ask if he or she would like to consent to staying in the Registry. A copy will be sent to your Paediatric Nephrologist. If there is no reply to this a further invitation will be sent at 18 years of age. If your child does not consent for himself or herself after that it will be assumed that they do not wish to remain in RaDaR, their record will be frozen and no further contact made. They could reactivate their participation later if they wish.

Who is responsible for RaDaR?

The Registry was set up as a joint initiative of the Renal Association of Great Britain, the British Association for Paediatric Nephrology, and the UK Renal Registry. It was started with funding from the Medical Research Council and Kidney Research UK. The National Registry is governed by the UK Renal Registry. The Registry has been approved by the North Somerset and South Bristol Research Ethics Committee, reference 09/H0106/72.

What happens if something goes wrong?

If you have any concerns about the conduct of the Registry you should raise it immediately with your kidney specialist. If this does not quickly resolve your concern you should contact the UK Renal Registry team at the address below.

The UK Renal Registry

Southmead Hospital
Bristol
BS10 NB
0117 959 5666