

National Registry of Rare Kidney Diseases (RaDaR)

Patient information sheet for children.

Thank you for taking a moment to read this information sheet. You are being asked to join in to find out more about kidneys and why they sometimes go wrong. Please ask if you have any questions.

The problem with your kidneys is rare – that means not many people have it. Doctors want to know more about it (and so do families!) but it is difficult to find out.

So we have set up a new group. This is called RaDaR and will collect information on people from all over the United Kingdom.

There are already doctors and scientists working to try and find out about your illness and they are going to start working together to find out more. If you and your family agree, information about you and how your kidney problem has affected you (like what age you were when you first got it and what medicine your doctor gave you) will be put on the computer database.

You and your family can also look at the information on the computer with a special password. Your kidney doctor will know all about it and can talk to you about it.

Sometimes the doctors and scientists may find out something which helps and they will let you, your family and your doctor know.

You have to have a password to read the computer program so only you and a few people can see the information about you.

Do you want to ask any questions now?