

# **SPRUN**

Scottish Paediatric Renal and Urology Network

# Rituximab for paediatric renal conditions Information for patients, parents and carers

This document has been prepared by NHS National Services Scotland (NSS) on behalf of SPRUN. Accountable to Scotlish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. The SPRUN Network is a collaboration of stakeholders involved in care of children and young people with kidney and bladder conditions throughout Scotland, who are supported by an NSS Programme Team to drive improvement across the care pathway.

All content is available under the <u>Open Government Licence v3.0</u> except for graphic assets and where otherwise stated.

Endorsed June 2023 Review June 2026 NSD610-026 V1

# **Scottish Paediatric Renal and Urology Network**

Rituximab for Paediatric Renal Conditions

# Why is it important for my child to receive rituximab?

Rituximab belongs to a group of medicines called immunosuppressants. Rituximab is used to reduce the activity of the immune system which stops the kidney disease process – for example, stopping a relapse in nephrotic syndrome.

## How does it work?

The immune system makes antibodies and immune cells, which are in a child's/young person's body to fight infections, such as bacteria and viruses.

In certain illnesses, the immune system becomes too active. Rituximab will reduce the activity of B cells in the immune system, thus preventing the disease process – for example, relapse in nephrotic syndrome or disease recurrence in other conditions.

By reducing the activity of the immune system, Rituximab usually prevents the need for steroids or other immunosuppressants.

#### What are the benefits of rituximab?

- 1) A single dose can last anywhere between 6 and 18 months.
- 2) As it dampens the immune system for a long period, it usually reduces the requirement for steroids and/or other immunosuppressants.
- 3) Blood monitoring is not required as frequently as for patients who are on other immunosuppressants.
- 4) It is generally well tolerated with less side effects than other immunosuppressants.

# Are there any possible side effects?

#### 1) Allergic reactions

The most common side effect during the infusion, which starts slowly and increases as tolerated, is similar to that of an allergic reaction. Most reactions are mild and can be alleviated with oral medication and/or a slower rate of infusion.

As a slower rate is better tolerated, this may mean that the infusion takes up to 8 hours to complete.

#### 2) Increased risk of infections

As Rituximab reduces the immune system response, there is an increased risk of infection for the time that the body's immune system is dampened. Unlike an oral medication, Rituximab's effects cannot be stopped quickly if there are problems.

#### 3) Risk of reduction in immunoglobulins

Those who receive repeated doses of Rituximab are at a higher risk of reducing the amount of immunoglobulins (antibodies) produced. Immunoglobulins are important to fight infection. If this occurs it is usually short lived. In rare cases, where they do not recover, we many need to replace the immunoglobulins via an infusion.

# **Scottish Paediatric Renal and Urology Network**

Rituximab for Paediatric Renal Conditions

## 4) Rare neurological condition

Very rarely Rituximab may cause a rare neurological condition. This will be discussed with you prior to the infusion but it has never been reported in any child that has received Rituximab.

As Rituximab has been used for around 20 years, there may be much longer-term side effects that we are not aware of.

# How is rituximab given?

Blood tests will be needed beforehand. These are done in clinic before the day admission for the infusion.

Rituximab is given as an infusion (via a drip). This means a cannula (small plastic straw inserted into hand or arm) is inserted before the infusion. The infusion is given slowly over 6 to 8 hours. Most children and young people go home after their infusion. Initially only one dose may be required as this medication can be effective for 6 to 8 months.

#### Additional information

If whoever is receiving Rituximab has not had chicken pox before and if they are exposed to someone, who has it, you should contact your doctor straightaway.

Live vaccines cannot be given for the period that Rituximab has reduced the immune system. Please check with your renal team which vaccines are safe to be given and when.

## **Further information**

Can be found on the Scottish Paediatric Renal and Urology Network (SPRUN) website. sprun.scot.nhs.uk

If you require an alternative format, please contact <a href="nss.equalitydiversity@nhs.scot">nss.equalitydiversity@nhs.scot</a>, telephone: 0131 275 600

British Sign Language, please contact Scotland BSL: <u>Contact Scotland</u> (contactscotland-bsl.org)