



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

# Rituximab to treat demyelinating disorders

**The following information should be read in conjunction with the patient leaflet provided by the manufacturer. However, please note that this may differ from the manufacturer's information as we are specifically referring to the use of rituximab in children and young people.**

**This leaflet explains what rituximab is, how it is given and some of the possible side effects. Each person reacts differently to medicines, so your child will not necessarily suffer from every side effect mentioned. If you have any questions or concerns, please speak to your doctor, nurse or pharmacist.**

## What is rituximab?

Rituximab (brand name MabThera®) is a relatively new medicine which works on the immune system. It removes some of the white blood cells in the body which are called B cells. Removing these stops the production of antibodies that may play a role in your child's illness.

Rituximab is a disease-modifying drug (DMD) treatment used in the Neuroimmunology Center at Great Ormond Street Hospital (GOSH) for treating neurological problems caused by the immune system becoming mis-programmed or confused and attacking the nervous system. Examples of these conditions are Neuromyelitis Optica (NMO), Opsoclonus Myoclonus Syndrome, auto-immune encephalitis and Myasthenia Gravis. The decision on whether to use this treatment for your child's condition is a complex decision and should be made together with your Paediatric Neurologist.

## How is it given?

Rituximab is given once every week for four weeks through a needle placed in a vein (intravenous or IV infusion). The whole process takes four to five hours once established. It will be given on the Neurology Day unit at GOSH. There will be some flexibility around the day you come, but it is preferable not to delay significantly between treatments if possible.

## Who should not take rituximab?

Rituximab must not be given to patients who may be pregnant, are likely to become pregnant in the near future or are breastfeeding. If your daughter is ten years old or older, we will ask her about her periods and any possibility that she could be pregnant. Reliable contraception is advised for both male and female patients for twelve months after finishing rituximab.



## What are the side effects?

Like all medicines, this medicine can cause side effects, although not everybody gets them. Most side effects are mild to moderate but some may be serious and require treatment. Rarely, some of these reactions have been fatal.

### Infusion and allergic reactions

Many people experience some infusion related symptoms when being given rituximab. Symptoms can include: hives, itching, trouble breathing, chest pain, low blood pressure, dizziness, chills, nausea or flushing.

On account of this, one hour before we give the Rituximab we will give your child some paracetamol and antihistamine. The infusion may need to be slowed or stopped until the symptoms go away. These reactions are less likely to happen the second time. Rarely, people can experience an allergic reaction to the medicine – if this occurs, we will then stop the treatment, treat your child for the reaction and not give the rituximab again.

### Infections

Rituximab affects your immune system, and thus may increase the chance of your child getting an unusual or serious infection. This can include chicken pox, shingles and cold sores. If your child has previously had hepatitis B, this can also be reactivated. If your child has an infection at the time the infusion is due, this will need to be treated if necessary and the infusion delayed. We will do blood tests before we start treatment to see if your child has previously had any of these infections.

### Progressive Multifocal Leukoencephalopathy (PML)

Very rarely, rituximab has been associated with a rare brain infection caused by a virus, known as JC virus, changing, multiplying and spreading. This infection is known as Progressive Multifocal Leukoencephalopathy (PML). PML is associated with a high mortality and high chance of severe disability. Before starting treatment, your child will be offered a blood test to look for the anti-JC virus antibody. If your child is JC virus negative, the risk is known to be extremely low.

### Other side effects

Headache, feeling tired, urinary tract infections, joint pain, depression, diarrhoea, colds and coughs, low blood counts, increased tears and secretions, ringing sound in the ears, mouth ulcers, weight loss.

### Rituximab and other medicines

Always check with your doctor or pharmacist before giving your child any other medicine, including medicines on prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines. However, no medicines have been reported as interacting with rituximab.



## Important information

As rituximab affects your child's immune system, they should not be given any 'live' vaccines. The 'killed' or inactivated polio vaccine should be used instead of the 'live' form in patients taking rituximab. Ideally, your child should have completed their scheduled immunisations before taking rituximab. Your other children should be immunised according to the usual schedule but they should also receive the 'killed' or inactivated polio vaccine. If you have any questions about immunisations, please ask your doctor.

### Useful numbers

- GOSH switchboard: 020 7405 9200
- Pharmacy medicines information:  
020 7829 8608 Monday to Friday  
from 9am to 5pm

### Notes

Compiled by the Neuroimmunology Centre in collaboration with the Child and Family Information Group  
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