

Further information for patients

If you have any queries or concerns (before or after your appointment) please contact:

Kirsten Slaney, TSC Specialist Nurse
Tel. 01225 821810 Email: kirsten.slaney@nhs.net

Appointments queries

If you have any appointment queries, please contact:

Amanda Blyth, TSC Team Administrator
Tel: 01225 821545 Email: amanda.blyth@nhs.net

Our website has further useful information

http://www.ruh.nhs.uk/patients/services/clinical_depts/TSC

Royal United Hospitals Bath NHS Foundation Trust
Combe Park, Bath BA1 3NG
01225 428331 www.ruh.nhs.uk

Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format, or would like to feedback your experience of the hospital.

Email ruh-tr.PatientAdviceandLiaisonService@nhs.net or telephone 01225 825656.

Sirolimus Ointment for Facial Angiofibromas in Tuberous Sclerosis Complex



What is Sirolimus Ointment?

Sirolimus ointment is made with sirolimus (also known as rapamycin or rapamune) one of a group of drugs called mTOR inhibitors which can stop certain cells in the body from growing. Sirolimus ointment can treat the facial rash (angiofibromas) in tuberous sclerosis complex (TSC). Although sirolimus ointment is not licensed the oral preparation is commonly used and research supports its safety.

How to use Sirolimus Ointment

- You should apply a thin coating to the affected area once a day around 30-60 minutes before bedtime. Allow it to air-dry and then remove by gentle washing in the morning.
- Use extra care when you apply the ointment around the eyes, nose and mouth.
- Wash your hands immediately after using the ointment.
- If you are pregnant, think you might be pregnant or are breast feeding avoid using the ointment as Sirolimus is potentially toxic to an unborn baby.

Monitoring and Review

We will take a photo of your rash and complete a health quality of life assessment when you start treatment with sirolimus ointment. This means that we will be able to monitor any changes to your rash following treatment.

About six months after starting treatment we will offer you a follow up appointment in the TS clinic. We will take a follow up photo and complete a follow up health quality of life questionnaire.

Possible Side Effects

Mild irritation and a burning sensation are the most common side effects. Hydrocortisone cream can be used to treat this if needed, please see your GP if needed.

Long term side effects are not yet known but we would advise extra care in the sun.

It is important to always use sunblock especially on your face. If you develop any new moles on your face or any changes to existing moles on this treatment, please see your GP. If you have any concerns about possible side effects please contact either the TS nurse or your GP

Other Information

Sirolimus ointment will become out of date in three months. It should be stored at room temperature.

Your sirolimus ointment will be sent to you by the pharmacy department at the RUH. Please contact the TS clinic to request a new prescription.