

Further Information and Support

If you have any queries or concerns (before or after your appointment) please contact the TS Nurse.

Kirsten Slaney, Tuberous Sclerosis 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

Tuberous Sclerosis Association (TSA)

The TSA provides information, advice and support to individuals and families affected by TS. www.tuberous-sclerosis.org

Our website has further useful information
http://www.ruh.nhs.uk/patients/services/clinical_depts/TSC

Directions to the TS Clinic

Children's Centre Outpatients, Department B11
Royal United Hospitals Bath NHS Foundation Trust
Combe Park, Bath BA1 3NG

http://www.ruh.nhs.uk/finding/maps/800x600_maps/childrenscentre.gif

Please contact the Patient Advice and Liaison Service (PALS) if you need this leaflet in a different format, or would like to feedback your experience of the hospital. Telephone 01225 825656 or Email ruh-tr.PatientAdviceandLiaisonService@nhs.net

Bath Supraregional Tuberous Sclerosis Complex Service for Adults and Children



Bath Tuberous Sclerosis Complex (TSC) Clinic

The Bath TSC Clinic is dedicated to looking after people with TSC in a holistic manner. This means that we are uniquely able to deal with many aspects of care for both children and adults.

We accept referrals from across the UK and overseas, providing a specialist and expert service for our patients. We are the oldest and largest TSC clinic in the country. We aim to work as closely as possible with your local health care team, as well as any other agencies involved in your care

Who Are We?

The clinic is led by Consultants Prof Finbar O'Callaghan and Dr Ron Loh and is supported by Dr Sam Amin (Research Associate), Dr Farzana Hakim (Specialty Doctor/GP), Kirsten Slaney (Specialist Nurse) and a Medical Secretary.

We work with a wider team of doctors from neurology, radiology, neuropsychology and urology, who are all experienced in managing TSC. The service also has close links with the Neurosurgery, Plastic Surgery and Fetal Medicine departments in Bristol and Great Ormond Street Hospital in London.

What We Do

Our work falls into four main categories:

- Diagnosis of TSC and second opinions.
- Management of TSC, including ensuring regular screening for the complications of TSC.
- Genetic Counselling, with support, information and advice about this genetic condition.
- Advice and consultation to local health care services.

Your First Appointment

You may be referred to the TSC clinic because:

- It is thought you may have TSC.
- You have had a recent diagnosis of TSC .We can provide further information and support about your condition and help you to manage it.
- A close family member has TSC and you want to be checked to see whether you also have TSC.
- You have TSC and want further support in managing your condition and/or want to investigate treatment options.

At your first appointment we will:

- Ask you what you expect from your appointment and any questions you may have.
- Ask you about your medical history, including your medications, doses and any tests and scans you may have had. Please bring any relevant clinic letters with you.
- Carry out a detailed physical examination to look for any outward signs of TSC you may have.
- Discuss and agree with you a plan for further follow up.

Between Appointments

If you have any queries between clinic appointments, please contact the TSC Nurse (P.T.O), who will be able to provide advice and support or guide you to other appropriate services.

We are an outpatient service, so if you have an urgent medical concern, please contact your GP or phone 111 for advice.

Research in Bath

We have an active programme of research that includes clinical trials of new treatments and studies of TSC in the population.