**TUBEROUS SCLEROSIS MULTIDISCIPLINARY CLINIC REFERRAL**

**GUIDANCE FOR REFERRAL TO ALDER HEY HOSPITAL TUBEROUS SCLEROSIS COMPLEX – SERVICE**

***The Alder Hey TSC service is a multi-disciplinary service that specialises in assessment, surveillance and management of TSC***

* Thank you for choosing to refer your patient to our service. To make a referral please complete the form online or you can print it and send it to ‘TSC team at Alder Hey Children Hospital. Details are available on our Website.
* We accept referrals of children and young people with a diagnosis of TSC from 0 to 16 years of age
* Please be aware that the referral will be preferably accepted from the General or Community Paediatrician managing the child’s care. We will accept referrals from other specialities however they will need to ensure that a named Paediatrician who is our point of contact locally is involved in care. A named local Paediatrician is needed both for shared-care arrangements and to refer back to for any necessary treatment/clinical management
* The TSC Multidisciplinary team does not take over the care of the child. We will provide TSC surveillance, advice on TSC related management options and signposting, but clinical care will continue to be under the local team. We may organise some investigations in Alder Hey and some may be requested locally depending on individual circumstances, but we would be happy to review and advise on all investigations in our MDT for children under our service.

Referrals:

* We preferably accept referrals from the Consultant Paediatrician responsible for the care of the child with TSC to support a shared care process.
* If you are a specialist making a referral to the TSC service, then you need to ensure the local Paediatrician is also aware of the referral or the referral may be rejected
* We are able to accept the clinic letter if it has all relevant details required for the TS referral.

Please be aware:

* The referring Paediatric consultant would continue to be the professional managing and coordinating the overall care locally in conjunction with the TSC service
* For children reviewed in the TSC service including those who need treatment with Everolimus, we would agree a shared care plan whereby the local team organise relevant investigations as required
* We would request the local team to share all results & scans with the TSC team at Alder Hey Trust and to update us regarding any changes in clinical status or management plan. This will help in looking after the child efficiently and effectively.

Your continuous support will be always appreciated by our team

*Important* – This is a tertiary TSC multidisciplinary advisory service including advice and management of complex epilepsy, renal issues and neurosurgical management in shared care agreement with local team. We also provide management and surveillance of key problems related to Tuberous Sclerosis. This service does not replace or substitute primary and /or secondary care arrangements locally.

 



ALDER HEY TUBEROUS SCLEROSIS MULTIDISCIPLINARY CLINIC REFERRAL FORM

Name of Referring Paediatric Consultant:

Name of the trust:

Local Lead Paediatrician (If not the Referrer)

Demographic details of the child

|  |  |
| --- | --- |
| Full Name |  |
| Date of birth |  |
| NHS number  |  |
| Address |  |

Has the child received a confirmed diagnosis of Tuberous Sclerosis Complex: Yes/No:

|  |  |
| --- | --- |
| Diagnosis based on  | Details |
| 1. Clinical criteria
 |  |
| 1. Neuroimaging

( last scans- please share) |  |
| 1. Genetic testing undertaken?

  | Results -  |

Clinical problems (tick as appropriate)

|  |  |  |
| --- | --- | --- |
|  | Cardiac rhabdomyomas |  |
| 2. | Epilepsy |  |
| 3 | Developmental delay |  |
| 4 | Eye abnormalities |  |
| 5 | Kidney abnormalities |  |
| 6 | Skin |  |
| 7 | Other |  |

Current treatment/medication:

|  |  |
| --- | --- |
|  |  |

Previous treatment/medication

|  |  |
| --- | --- |
|  |  |

Clinicians involved in care: ( they will be copied into all communication)

|  |  |
| --- | --- |
|  |  |

Named Local Lead Paediatrician -contact details:

|  |  |
| --- | --- |
|  |  |

Any other relavant medical information or any specific concerns you would like us to address:

|  |  |
| --- | --- |
|  |  |

Signature of Clinician Date: