

# Integrated ‘one-stop’ multi-disciplinary clinic for children and young people with Tuberous Sclerosis Complex (TSC)

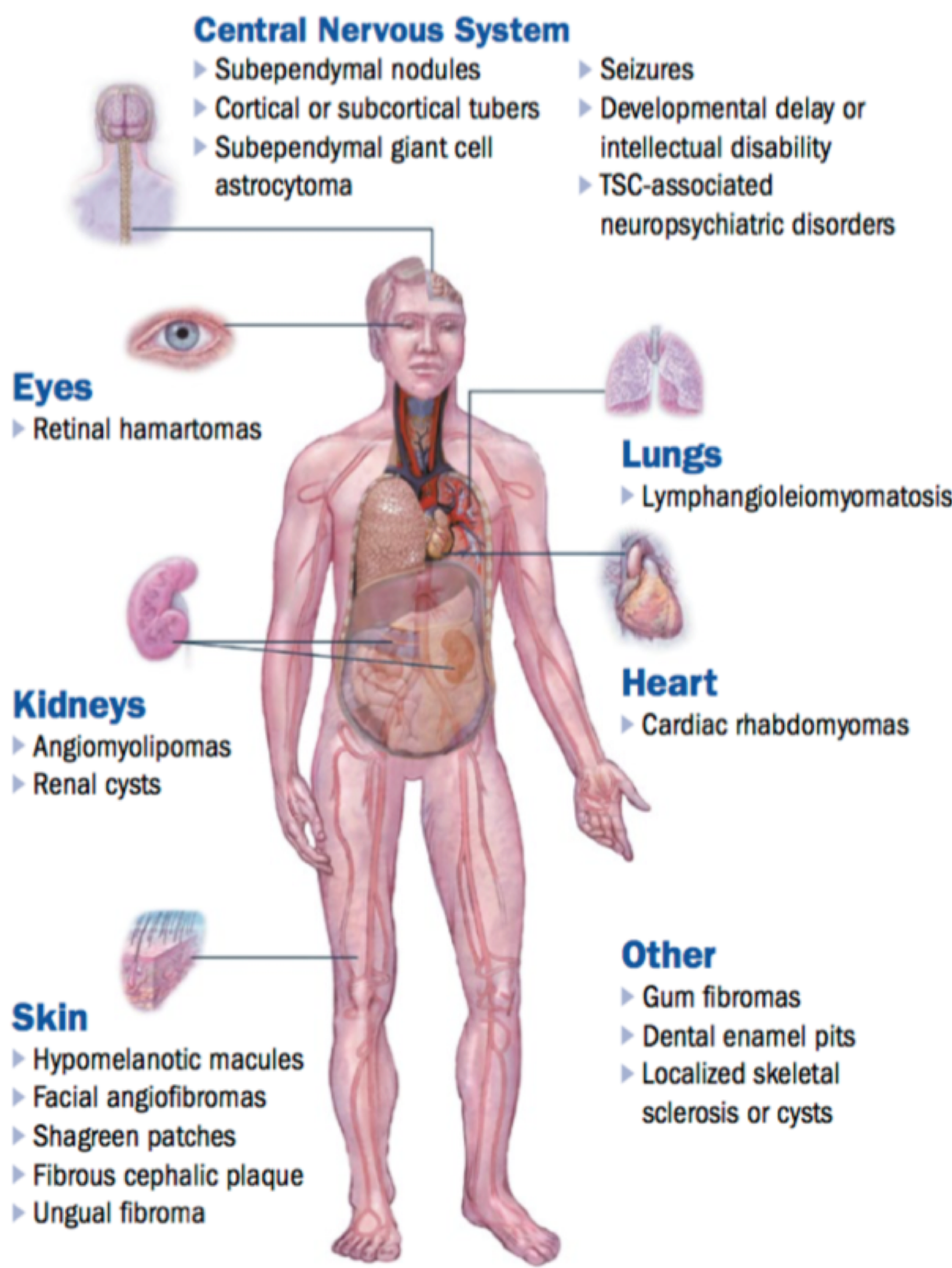
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### Introduction

#### TSC

- Complex, genetic disorder characterised by growth of benign tumours in various organs leading to epilepsy, renal, cardiac, skin, lung, liver and eye manifestations



- Multiple clinic appointments with different specialists is norm for patients affected
- Developmental delay and TSC-associated neuropsychiatric disorders (TANDS) are common complications of TSC but often not addressed

#### Aims:

The MDT TSC clinic was launched in 2016 with the following aims:

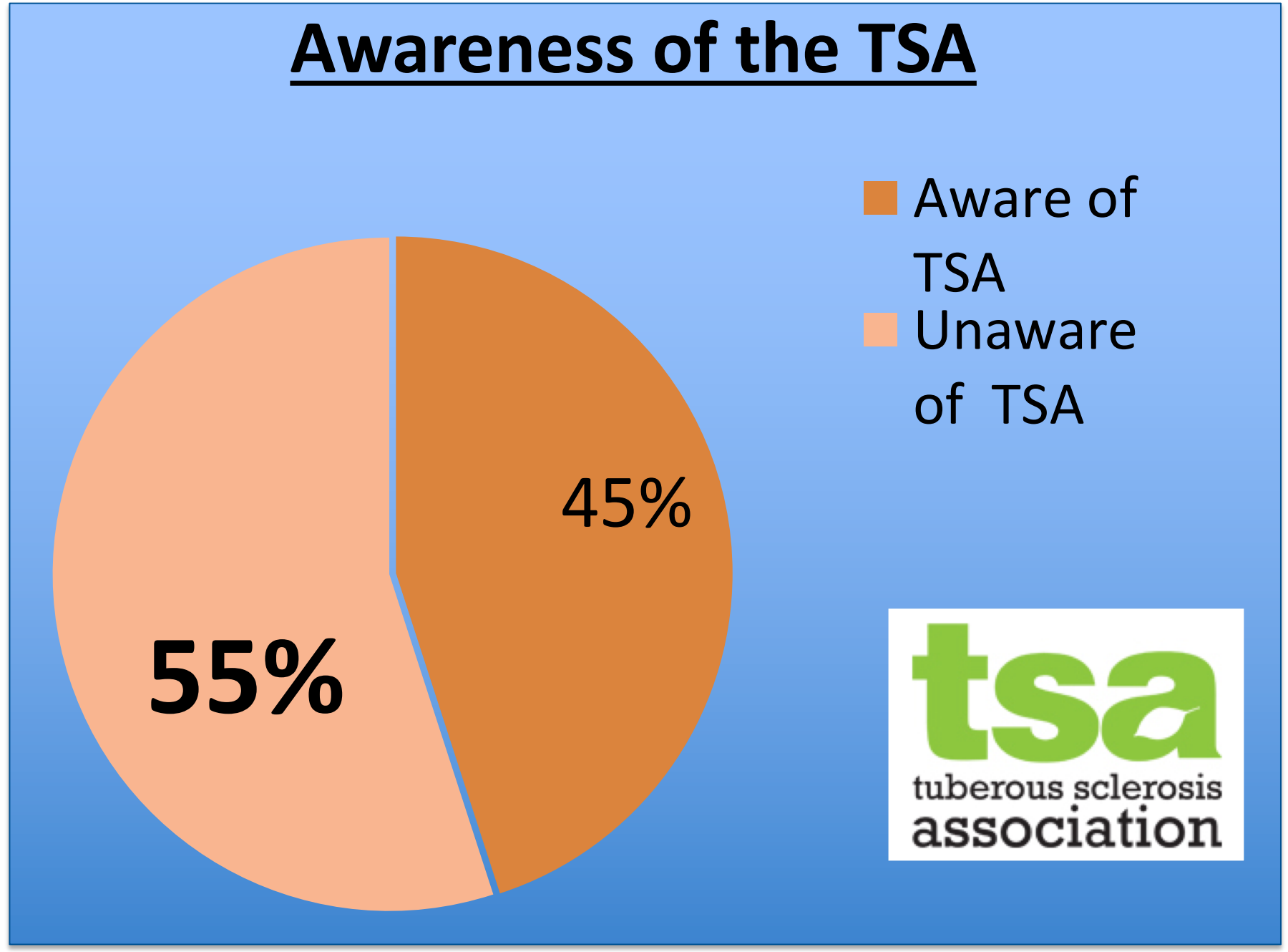
- To improve the care of children and young people affected by TSC by an integrated multidisciplinary team (MDT) ‘one-stop’ clinic
- To provide psychological assessment of TANDS

#### Methods:

- The MDT TSC clinic set up by coordinating Neurology, Nephrology, Oncology, Psychology Consultants, Roald Dahl Rare Disease Specialist Nurse and Tuberous Sclerosis Association Advisor in one appointment
- Psychology input was funded by a Pharma Joint Working Agreement

#### Results:

- 22 patients seen in first 6 TSC MDT clinics
- Appointment Burden before TSC MDT clinic:
  - Average appointment number/patient =
  - 5.3/year (range 0.6 - 11.7/yr.)
- Need for Psychology:
  - 40% of Patients in TSC clinic required further psychology input
  - 20% referred for formal Child and Adolescent Mental Health Service (CAMHS) review.
- Awareness Patient Support Organisation:



- Identification of patients with TSC:
  - 98 patients identified from different lists kept by specialties
  - Only 16 identified through coding
  - Average patient age 10.3 yrs. (range: 1.6 - 21.1 yrs.).
  - 38% had previous renal input but 42% had not had a renal ultrasound. (should be yearly)
  - 66% had neurology input but 33% had no brain imaging (should have at least one and then regularly if abnormality detected)
- Roald Dahl Rare Disease Specialist Nurses
  - Send Information Packs
  - Call families to discuss what their main concerns so in clinic team can focus on what is relevant to each family
  - Provide support between clinics

- Transition
  - Input from adult TSC transition team from adult sister hospital for patients > 16 years at the TSC MDT clinic

#### • Patient Feedback Questionnaire:

“Excellent!”

“having all the specialists together makes so much sense and they can explain in a way that we can understand”.

“this is a fabulous idea that saves us time”

“This should have been started a long time ago”

#### Conclusion:

The MDT TSC clinic has

- Improved coordination of patient care
- Highlighted need to ensure that imaging is regularly carried out according to best practice guidelines
- Identified high burden of psychological need
- Excellent feedback
- Families prefer the MDT TSC clinic to the previous multiple clinics



By your side