

# Rett Clinics and Regional Days in the United Kingdom



# Do you have a Rett Centre or a Rett clinic?

The UK does not have a dedicated medical/care centre which specialises in Rett syndrome.

- We have 5 specialist clinics in different parts of the country
- Although we do not have a dedicated Rett centre we run three Regional Days a year where families have access to specialists

# Where are clinics held?

- The clinics are usually held in a hospital setting
- They are run jointly by the National Health Service and Rett UK in different parts of the country

## Rett UK holds 5 clinics

- London - Children
- Manchester - Adults
- Cardiff - All ages
- Nottingham - Children
- Kent - Children

# How many people with RTT are seen each year?

- **At Clinics** - About 65 people with RTT are seen in clinics each year. Last year there were 56 children [under 18] and 9 adults
- **At Regional Days** - Between 120 and 150 people with RTT attend each year

# Where and how is the diagnosis carried out?

- Usually a genetic or clinical diagnosis is made before attending the clinic
- Diagnosis is carried out across the UK by General Practitioners [Family Doctors], Paediatricians, Neurologists and Geneticists

# What specialisms are provided at Clinics?

- Neurology
- Paediatrics
- Medical genetics and genetic counselling
- Psychological Medicine
- Nutritionist, swallow therapist
- Dietetics
- Therapists – Speech & Language, Music, Physiotherapy & Occupational Health

# What clinical examinations are carried out?

- Consultation
- Physical Examination
- Physiotherapy
- Occupational Therapy
- Music Therapy



# What happens after the Clinic?

A written report is provided to the family and their Doctor [General Practitioner] with advice as to what specialist help is needed.

# Is there assistive technology?

- At Regional Days families have access to information about augmentative and alternative communication technology [AAC]  
This would include e.g. Eye-gaze technology
- At Clinics families receive advice from a speech and language therapist about AAC

# Is there a connection between the Clinic or Regional Day and research labs?

- One of the clinics is held at a genetic centre which has a research facility which includes therapeutic research
- Rett UK highlights areas where families can assist with research
- Genetic samples are sent to Edinburgh and results are sent back to local genetic centres
- At Regional Days and in '*Rett News*' families are given information about assisting research

# Is there a social or advisory service for families?

- Professional Support Workers from Rett UK attend all of the clinics, providing support and information, before, during and after clinic appointments
- Rett UK also provides links to specialists to families who are in crisis

# How are the Clinics and Regional Days financed?

- If the Clinic is held outside the area where the family lives, they are funded to attend clinics by local Clinical Commissioning Groups
- If the Clinic is held inside the area where the family lives they are funded by their local Health Authority
- Regional Days are free and are funded by Rett UK