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Media Release

RUH Bath team backs Rare Disease Day

World Rare Disease Day (February 28) is being supported by a team from the Royal United Hospital, Bath that's a leader in the research and treatment of Tuberous Sclerosis Complex (TSC) – a rare genetic condition that affects one baby in 6,000 births in the UK.

A disease or disorder is defined as rare in Europe when it affects fewer than 1 in 2000 people. One in 20 people will live with a rare disease at some point in their life. Despite this, there is no cure for the majority of rare diseases and many go undiagnosed.

Rare Disease Day is an opportunity to highlight conditions like TSC and the work of medical teams like that at the RUH. TSC causes mainly non-cancerous (benign) tumours to develop in different parts of the body. The tumours most often affect the brain, skin, kidneys, heart, eyes and lungs.

It is present from birth, although it may not cause obvious problems immediately. Associated health conditions can include epilepsy, learning difficulties or a build-up of fluid on the brain.

The RUH Bath's TSC Clinic is the oldest and largest in the country, looking after more than 250 patients with referrals from across the UK and overseas.

Dr Ron Loh, Consultant Paediatrician and Joint Head the TSC Service, said: "Our team has unparalleled expertise and specialist knowledge in looking after children and adults with TSC. We have recently expanded our team to improve continuity and to strengthen our service. We have a strong, proud tradition of research in Bath and many of our patients have been part of pioneering trials for new treatments for TSC."

The TSC Clinic works closely with other specialities at the RUH including urology, radiology and neuropsychology, and has strong links with neurosurgery and plastic surgery departments in Bristol, the Bristol Royal Hospital for Children and Great Ormond Street Hospital in London.

For more information about the TSC Clinic, visit our website
http://www.ruh.nhs.uk/patients/services/clinical_depts/TSC/research.asp

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The RUH is also part of the 100,000 Genomes Project, set up within the NHS to investigate the genetic causes of cancer and rare disease. Around 1,500 patients with rare diseases have consented to be part of the project through the West of England Genomics Medicine Centre, one of a network of 13 regional GMCs in England, with a further 200 patients with cancer also consenting since the centre was set up at the end of 2015.

Ends

Notes to Editor:

- The Royal United Hospitals Bath NHS Foundation Trust provides acute treatment and care for a catchment population of around 500,000 people in Bath, and the surrounding towns and villages in North East Somerset and Western Wiltshire. The hospital provides healthcare to the population served by four Clinical Commissioning Groups: Bath & North East Somerset CCG, Wiltshire CCG, Somerset CCG and South Gloucestershire CCG.
- The Trust provides 565 beds and a comprehensive range of acute services including medicine and surgery, services for women and children, accident and emergency services, and diagnostic and clinical support services.
- In 2015 The Royal United Hospitals NHS Foundation Trust was acquired the Royal National Hospital for Rheumatic Diseases (RNHRD) NHS Foundation Trust. The RNHRD treats patients from across the country offering services in rheumatology, chronic pain and chronic fatigue syndrome/ME.
- The RUH is changing - we have an exciting programme of redevelopment underway transforming our site and further improving the services we provide. The Trust is now working towards building a purpose built RNHRD and Therapies Centre and a new Dyson Cancer Centre. For more details visit: www.ruh.nhs.uk/about/fit_for_the_future
- For more information about the Royal United Hospitals Bath NHS Foundation Trust visit: www.ruh.nhs.uk

