RET UK Collaborative Network
Invitation for collaboration in a new research project:
"UK wide Review of treatments and outcomes in Children and Adults with MEN2B caused by 918 RET mutations."

Dear Colleagues,

Multiple Endocrine Neoplasia type 2 (MEN2) is a rare disease caused by the mutation of RET protooncogene and a prevalence of 1 in 30.000 people. There are about 2000 patients with this condition in the UK but little is known about how quickly they are diagnosed, what treatments they receive and what are the outcomes of various therapies. 5 years ago we have formed RET UK Collaborative Network (RET UK) with an aim of facilitating the exchange of ideas and collaborative initiatives leading to innovative projects and grant applications. We hope that coordinating research with ongoing clinical care will encourage recruitment into laboratory based projects and clinical trials. We believe that such a network will also enable earlier diagnosis of RET causative disease and ensure better treatment options for patients and improve clinical outcomes.

The work which has been undertaken by the RET UK so far included review of outcomes of prophylactic thyroidectomies in children with MEN2 who had surgery between 1995 and 2017, initiation of innovative treatment with RET specific tyrosine kinase inhibitors in children with MEN2 and advanced medullary thyroid cancer (Selpercatinib) and organisation of RET&CRICK Conference in 2019 dedicated to conditions caused by RET mutations (papers and programme attached).

Our next project is a UK-wide review of current care and outcomes for children and adults diagnosed with Multiple Endocrine Neoplasia Type 2B (MEN2B) due to Met918Thr *RET* mutations. This is a very rare diagnosis, but it is well known to be associated with early development of medullary thyroid cancer, poor quality of life due to multiple pathologies and decreased life expectancy. Many of patients with MEN2B have de novo mutations therefore there is no family history, which makes it difficult to be diagnosed in a timely fashion.

We would be interested in collaborating with clinicians who knew of patients fitting these criteria and to hear from patients who were diagnosed with MEN2B. If you are interested in contributing to this study, please contact Dr. Sinead McGlacken-Byrne (s.mcglackenbyrne@nhs.net) or Mr Tom Kurzawinski (tom.kurzawinski@nhs.net) for further information.

The data collection is registered as a nationwide study for service evaluation at GOSH (reference number 3158) and will collect retrospective details form hospital records.

We are looking forward to hearing from you

Best wishes,

Dr Sinead McGlacken-Byrne, Paediatric Endocrinology GRID Trainee
Mr Tom Kurzawinski, Consultant Endocrine Surgeon
Caroline Brain, Consultant Paediatric Endocrinologist
Louise Izatt, Consultant in Clinical Genetics, Guy's and St Thomas' NHS Foundation Trust