



## **TFE Renal Cell Carcinoma Research Initiatives & Registry**

Our mission: To bring together physicians and scientists in a collaborative pursuit to better understand TFE Renal Cell Carcinoma, and develop better treatments and outcomes for patients everywhere.

TFE renal cell carcinoma (TFE RCC) (otherwise known as translocation renal cell carcinoma- tRCC) is a specific subtype of renal cell carcinoma that is caused by a translocation mutation between two different genes, causing an overexpression of genes and cancer cells to grow. TFE RCC is still a relatively new disease, being formally recognized by the WHO in 2004. As such, much about its biological behavior is unknown.

Although it is a rare type of cancer, TFE RCC, largely thought of as a cancer of children, adolescents and young adults, accounts for approximately 1/2 of all pediatric RCCs and up to 5% of adult RCCs. Currently, there are no formal treatment recommendations available for TFE RCC and no dedicated therapeutic trials have been conducted. Limited retrospective studies have been performed previously, but more data gathered over a long term period of time and from a large number of patients is needed to gain better insight into TFE RCC. The TRRI registry is aimed to provide this long term follow up needed to better understand prognosis and outcomes of disease, and the consortium to conduct hypothesis driven research to develop better treatments options by developing tumor models and performing drug tests and screenings.

### **What is a registry?**

A registry is a centralized source of data gathered from patient's clinical information that continually expands as patients are enrolled. Through this growing registry we are able to capture data from a large number a patients with varying demographic backgrounds and pool it together in a way that will allow for better characterization and understanding of TFE RCC.

The TRRI Registry is a key component of the TRRI Consortium, with its data supporting hypothesis driven research with the long term goal of developing better treatment options and outcomes for TFE RCC patients everywhere.

Please visit [www.trccregistry.org](http://www.trccregistry.org) for more information on the TRRI consortium and registry, and how to participate. You can contact registry staff with any questions at 1-844-RCC-TRRI or [TRRI@cchmc.org](mailto:TRRI@cchmc.org).