



UMBRELLA Newsletter



Issue # 1 December 2019

What is the UMBRELLA study?

- UMBRELLA aims to improve survival and provide the best treatment options for children with kidney tumours
- UMBRELLA is testing how changes in the tumour DNA (genetic make-up) and scans can predict relapse
- It is the continuation of the IMPORT study which started in the UK in 2012 and has now been renamed to UMBRELLA
- It has opened worldwide in 2019
- Treatment for children at present follows national clinical guidelines agreed following the last clinical trial, SIOP WT 2001 and will be uniform across the countries that participate in UMBRELLA
- The UMBRELLA study is funded by The Little Princess Trust and Bethany's Wish in conjunction with CCLG

What's happening now?

- UMBRELLA has registered 92 patients from 9 countries to date, including 10 from the UK
- This means there will be much larger groups of patients and results can be used to change future clinical practice as we will have more data
- UMBRELLA is planned to run until Dec 2022
- UMBRELLA will help us choose important 'biomarkers' and will help us to personalise future treatment
- Some of these 'biomarkers' include changes in the tumour DNA (1q gain) or volume of blastemal cells left in the tumour after chemotherapy
- UMBRELLA will also let us compare internationally how kidney tumours are first diagnosed and why there may be differences between countries

Wilms team with USA WAGR parents, 2019



Dr Stephen Marks (GOSH), WAGR association members: Shari Krantz, Kelly Trout, Jenny & Adam Gunckle with the renal tumour team: Kathy Pritchard-Jones, Suzanne Tugnait, Reem Al-Saadi

Achievements in the last year

- Research findings presented at several conferences and study group meetings stimulated international discussion on tumour sampling methods, biopsy and follow up scans requirements
- Published new updated treatment guidelines for all renal tumour patients which are available on the CCLG website
- The National Renal Advisory Panel that we established to allow discussion of complex cases across the UK and Ireland now meets twice a month
- Continued involvement of parents in our research through discussion at the CCLG Childhood Cancer Conference 2019, London, Patient Public Involvement meeting in SIOPE Prague, May 2019
- Met with WAGR parents from the USA in London 2019
- Presented 6 abstracts at SIOPE Lyon, 2019
- New Clinical Research Fellow, Dr Kristina Dzhuma joined the team to provide Central Radiology Review and surgical research

Upcoming PPI meetings in 2020

- 27-28 Jan CCLG Winter meeting, Nottingham
- 4-8 May SIOPE, Valencia
- August WAGR PPI, London
- 4 Sept CCC20
- TBC 2 PPI meetings in London



Would you like to support research into childhood kidney cancers or join our group? Contact us below for more information.

