



UMBRELLA NEWSLETTER

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Issue 3 - December 2022

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Updates on the UMBRELLA study and associated projects

The **UMBRELLA study** has been implemented as an amendment to the IMPORT study across the UK since 2019. The national sponsor continues to be GOSH and the international coordination is under the auspices of the SIOF Renal Tumours Study Group (SIOF-RTSG).

As part of a recent approved amendment, the UMBRELLA study is funded to continue with a new end date set to the 31st of January 2024. Prof Kathy Pritchard-Jones has retired from her position as chief investigator and is replaced by Dr Tanzina Chowdhury, oncology consultant at Great Ormond Street Hospital for Children.

The international study has registered over 2030 patients from 26 countries, some of which have joined the study for the first time. The UK recruited 268 patients up to the third week of December 2022 with 19 UK centres currently registering patients through the eRDE system (ALEA). One centre is still pending to open UMBRELLA but currently registering their renal tumour patients on IMPORT which since 2012 has recruited 724 patients.

MESSAGE TO UK PIs to share with clinical colleagues and data managers:

Please complete all pending IMPORT/UMBRELLA CRFs as data completion is key when running data analysis and completing manuscripts.

A request to surgeons, pathologists and radiotherapists in each centre please complete the CRFs sent to you by your data managers promptly.

In previous years (2020 and 2021) several projects were created and have progressed successfully over time, including:

- The Little Princess Trust Wilms Tumour Knowledge Bank - a collaboration between UCL/GOSH and the Sanger Centre, Cambridge with Dr Sam Behjati as co-principal investigator.
- Whole Genome Sequencing (WGS) collected in the UK and Germany with a focus on metastatic cases and infants diagnosed under the age of 12 months.
- Liquid biopsy study (whole exome sequencing on ctDNA from plasma of patients with Wilms Tumour diagnosis) in conjunction with Dr Gudrun Schleiermacher, Paris.
- Analysis of microRNAs in diagnostic serum, with Dr Matt Murray, Cambridge.
- A high-throughput study using Tissue Microarray (TMA) to evaluate the role of a panel of immunohistochemical markers using data from the SIOF2001, IMPORT and UMBRELLA studies has been developed in conjunction with the University of Liverpool.
- Predicting the % of stromal tissue in Wilms Tumours using Advanced Diffusion Image analysis of MRI scans

The Little Princess Trust Wilms Tumour Knowledge Bank

Despite the delays that the COVID-19 pandemic caused, the Knowledge Bank Team has made great progress. Dr Taryn Treger (clinical research fellow and PhD candidate, based in Cambridge's Sanger Institute) and Miss Aleksandra Letunovska (biomedical scientist, based at UCL Great Ormond Street Institute of Child Health) are now part of our team. Dr Treger is carrying out the analysis of the sequencing data from hundreds of Wilms tumour patients from the UK, Germany and the Netherlands. One of her remarkable findings was presented at the annual SIOF congress held virtually in October 2021 – the planned congress location was Hawaii, hence the garlands in this team photo!



Dr Guillaume Morcrette, a pathologist from Paris came to spend one year with our team. His research focused on local stage I and II Wilms tumours; his findings were presented at the SIOF 2021 congress. He collaborates with us remotely upon his return to France.



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Meetings 2022

Several meetings were held during 2022 which represented a great opportunity to share new developments, progress of current projects and future perspectives in cancer research, including:

CCLG Renal SIG	Virtual meeting, January 2022
CCLG Winter Meeting	Nottingham, April 2022
SIOPE Annual meeting	Valencia, 21-25th March 2022 (virtual)
SIOP RTSG GA	Seville, 27-29th June 2022
International paediatric renal tumour Biology Meeting	Marseille, 7-9th Sept 2022
54th SIOP Congress 2022	Barcelona, 28th Sept - 1st Oct 2022 (hybrid)
CCLG Renal SIG	London, 7th October 2022
Meeting with funders (LPT)	Hereford, 21st November 2022

Communication and Dissemination opportunities



Outcomes of the IMPORT study were presented by Ms Reem Al-Saadi at the **Annual NCRI conference** held virtually in November 2021, titled "Efforts to achieve earlier diagnosis of renal tumours in childhood are required to improve survival rates in the UK and Ireland"

Prof Kathy Pritchard-Jones was the Keynote speaker at the **CCLG Winter Meeting 2022** held in Nottingham. Huge congratulations as she also received the Lifetime Achievement Award!

SIOP RTSG 2022 Annual meeting – Seville, Spain. Held in person, represented a great opportunity to overview and discuss updated data from the UMBRELLA study at an international level.

SIOP 2021 (virtual) & SIOP 2022 (in person - Barcelona) Annual Congress

Four abstracts were submitted and presented:

1. Single cell derived organoids from infant Wilms tumour reveal novel insights into the REST tumour suppressor gene (presented by Dr Taryn Treger)
2. Stage II Wilms tumours: Do they all need the same treatment? (presented by Dr Guillaume Morcrette)
3. Outcomes of patients with relapsed low/intermediate-risk Wilms tumour after upfront treatment with Vincristine and Actinomycin-D only, based on the SIOP-93-01 and 2001 protocols (presented by Dr Alissa Groenendijk)
4. Adherence to protocol recommendations for children with Wilms tumour in two consecutive studies in the UK and Ireland – Does variation matter? (presented by Suzanne Tugnait)

11th International paediatric renal tumours biology meeting – Marseille, France

Dr Taryn Treger presented data from the LPT Wilms Tumour Knowledge Bank with a focus on predisposition genes on bilateral cases. Dr Harriet Rogers presented findings from a radiology physics study that looked at WT patients' MRI scans. Dr Daniyal Jaffrey investigated the lymphatic vessel structure in Wilms tumours.

Prof Kathy Pritchard-Jones and Ms Reem Al-Saadi were invited to visit the 57357 Children's Cancer Hospital Egypt, where they heard presentations from the Wilms tumour team on their current protocols, outcomes and associated research and participated in a **Global Health 2-day Meeting**. This allowed a broader overview of the clinical and research network of childhood cancer centres in Egypt and exploration of further opportunities for collaboration.

Many thanks to the **Pathology Department at GOSH** and all the support provided during 2022!

A meeting was held in the **Little Princess Trust** headquarters in November 2021 & November 2022 in Hereford, UK. Great opportunity to share the progress of current projects and discuss future plans.



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Upcoming Meetings and Events in 2023

CCLG Annual Conference	Nottingham, 20-21 March 2023
SIOPE 2023 Annual Meeting	Valencia, 8-12 May 2023
SIOP RTSG Annual Meeting	Wroclaw, 22-23 June 2023
CCLG Renal SIG	TBC
SIOP 2023 Congress	Ottawa, 11-14 October 2023

Publications

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Published booklets for patients, parents and carers!



- ✓ A Parent's Guide to Kidney Tumours
 - ✓ Wilms Tumour in Children
 - ✓ Treatment Options for Relapsed Wilms Tumour in Children
- Available for free for families affected by renal tumours



Acknowledgments



Many thanks to all our supporters, contributors and funders, without your help the progress and achievements would not be possible!



Seasons Greetings from the UK UMBRELLA Team



From left to right: Dr Kristina Dzhuma, Ms Reem Al-Saadi, Dr Guillaume Morcrette, Dr Angela Lopez, Miss Aleksandra Letunovska, Dr Tanzina Chowdhury, Prof Kathy Pritchard-Jones, Dr Richard Williams, Dr Susan Shelmerdine, Ms Suzanne Tugnait, Prof Gordan Vujanic.



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