



# UMBRELLA Newsletter



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Issue 2 – 11<sup>th</sup> January 2021

## Update on the UMBRELLA study & 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 SIOP Renal Tumours Study Group (SIOP-RTSG).
- Despite the temporary halt to recruitment because of COVID19, the international study has registered 581 patients from 17 countries, some of which have joined a study for the first time. The UK recruited 80 patients. The first report has been shared with the RTSG Steering Committee.
- 16 UK centres are registering patients through the eRDE system (ALEA), and the remaining 3 UK centres have approved the study and will open soon. These 3 centres are continuing to register their renal tumour patients on IMPORT which since 2012 has recruited 702 patients.

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

1. Please complete all pending IMPORT CRFs, especially End of Treatment and Follow Up forms which are needed to complete manuscripts.
  2. A request to surgeons, pathologists and radiotherapists in each centre please complete the CRFs sent to you by the data managers promptly.
- On the 27<sup>th</sup> Feb 2020 we launched our newly funded project named after the charity that's kindly donated the funds, The Little Princess Wilms Tumour Knowledge Bank; a collaboration between UCL/GOSH and the Sanger Centre, Cambridge, PI: Dr Sam Behjati.
  - To date, Whole Genome Sequencing (WGS) has been performed on 250 Wilms tumours collected in the UK and Germany with a focus on metastatic cases and infants diagnosed under the age of 12 months. A further 100 WT will have WGS, with results expected in spring 2021.
  - Despite the delays caused by lockdown, we also managed to continue two projects to assess circulating molecular biomarkers – 1. a liquid biopsy study (whole exome sequencing on ctDNA from plasma of WT patients) in conjunction with Dr Gudrun Schleiermacher, Paris, and 2. Analysis of microRNAs in diagnostic serum, with Dr Matt Murray, Cambridge.

## UK PPIE meeting, 6<sup>th</sup> Feb 2020



We held a parent/patient workshop to discuss linking clinical trial data to national cancer registries and other routine health care data for long term outcomes research. This was seen to add value to the original trials and be an important priority area.

## RTSG General Assembly & Brazilian PPIE Meeting

The annual SIOP RTSG GA took place in Rio de Janeiro on 11-13<sup>th</sup> March 2020, hosted by Dr Beatriz De Camargo & Dr Joaquim Caetano Aguirre Neto for the Brazilian WT group. Five UK delegates attended the meeting which also included a Brazilian parents and survivors group meeting.



## Updated CCLG clinical guidelines

The clinical guidelines that accompany the amendment of IMPORT into the UMBRELLA study explain the changes that have updated our previous standard of care, based on the SIOP WT 2001 randomised trial, to incorporate new evidence from international partners on significance of tumour volume after pre-op chemo and definitions of metastatic disease. There is also an agreed international standard approach to treatment of relapsed Wilms tumour that incorporates our national experience from UKWR. The updated guidelines are published on the CCLG website, members' area.

### Recent Abstracts

- **SIOP 2020 presented abstracts:**
  - Variation in adherence to protocol recommendations for pre- and post-operative treatment of children with Wilms tumour in two consecutive studies in the UK and Ireland (oral, S Tugnait).
  - Wilms tumours with intravascular extension in the UK and Ireland IMPORT study: reasons for stage III (poster, K Dzhusma).
- An update on the UMBRELLA study was presented during the CCLG Winter meeting on the 27-28 January 2020, and a trials update was presented during the NCRI trials meeting on the 29<sup>th</sup> January 2020
- Poster at CCLG conference Jan 2020: S Tugnait et al, Review of chemotherapy delivery for Wilms tumours in the UK and Ireland in the SIOP WT 2001 and IMPORT studies

## Relevant meetings in 2021

UK Renal SIG	Virtual meeting 29 <sup>th</sup> January 2021
CCLG Winter Meeting	Virtual 22-24 <sup>th</sup> Feb 2021
SIOPE Annual meeting	Valencia Virtual meeting 26-30 <sup>th</sup> April 2021
SIOP RTSG GA	Utrecht 24-25 <sup>th</sup> June 2021 (TBC)
SIOP RTSG Biology Meeting	Marseille 22-24 <sup>th</sup> Sept 2021 (TBC)
CCLG Renal SIG	London 10 <sup>th</sup> Sept 2021 (TBC)
53 <sup>rd</sup> SIOP congress 2021	Honolulu 21-24 <sup>th</sup> October 2021 (hybrid meeting TBC)



UK UMBRELLA Team



UMBRELLA email address: [GOS-tr.Umbrella@nhs.net](mailto:GOS-tr.Umbrella@nhs.net)



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## Submitted Manuscripts

1. Setting International Standards for Parent and Patient Involvement and Engagement in Childhood, Adolescent and Young Adult Cancer Research: A European Collaborative Case Study; A. Polanco, R. Al-Saadi, S. Tugnait, N. Scobie, K. Pritchard-Jones; submitted in November to Cancer Reports.
2. Long-term renal function in children with Wilms Tumour and constitutional WT1 pathogenic variant; M Falcone, K Pritchard-Jones, J Brok, W Mifsud, R Williams, K Nakata, S Tugnait, R Al-Saadi, L Side, J Anderson, C Duncan, S Marks, D Bockenbauer, T Chowdhury; submitted to Pediatric Nephrology
3. Characteristics and outcome of Pediatric Renal Cell Carcinoma patients registered in the International Society of Pediatric Oncology (SIOP) 93-01, 2001, and UK-IMPORT database: A report of the SIOP-Renal Tumor Study Group. Justine van der Beek et al.

## Recent Publications

1: Lai AG, Pasea L, Banerjee A, Hall G, Denaxas S, Chang WH, Katsoulis M, Williams B, Pillay D, Noursadeghi M, Linch D, Hughes D, Forster MD, Turnbull C, Fitzpatrick NK, Boyd K, Foster GR, Enver T, Nafilyan V, Humberstone B, Neal RD, Cooper M, Jones M, Pritchard-Jones K, Sullivan R, Davie C, Lawler M, Hemingway H. Estimated impact of the COVID-19 pandemic on cancer services and excess 1-year mortality in people with cancer and multimorbidity: near real-time data on cancer care, cancer deaths and a population-based cohort study. *BMJ Open*. 2020 Nov 17;10(11):e043828. doi: 10.1136/bmjopen-2020-043828. PMID: 33203640; PMCID: PMC7674020.

2: Hol JA, Jongmans MCJ, Sudour-Bonnange H, Ramírez-Villar GL, Chowdhury T, Rechnitzer C, Pal N, Schleiermacher G, Karow A, Kuiper RP, de Camargo B, Avcin S, Redzic D, Wachtel A, Segers H, Vujanic GM, van Tinteren H, Bergeron C, Pritchard-Jones K, Graf N, van den Heuvel-Eibrink MM; International Society of Pediatric Oncology Renal Tumor Study Group (SIOP-RTSG). Clinical characteristics and outcomes of children with WAGR syndrome and Wilms tumor and/or nephroblastomatosis: The 30-year SIOP-RTSG experience. *Cancer*. 2020 Nov 4. doi: 10.1002/cncr.33304. Epub ahead of print. PMID: 33146894.

3: Nakata K, Colombet M, Stiller CA, Pritchard-Jones K, Steliarova-Foucher E; IICC-3 Contributors. Incidence of childhood renal tumours: An international population-based study. *Int J Cancer*. 2020 Jun 16. doi: 10.1002/ijc.33147. Epub ahead of print. PMID: 32902866.

4: Gupta S, Aitken J, Bartels U, Bhakta N, Bucurenci M, Brierley JD, De Camargo B, Chokunonga E, Clymer J, Coza D, Fraser C, Fuentes-Alabi S, Gatta G, Gross T, Jakab Z, Kohler B, Kutluk T, Moreno F, Nakata K, Nur S, Parkin DM, Penberthy L, Pole J, Poynter JN, Pritchard-Jones K, Ramirez O, Renner L, Steliarova-Foucher E, Sullivan M, Swaminathan R, Van Eycken L, Vora T, Frazier AL. Development of paediatric non-stage prognosticator guidelines for population-based cancer registries and updates to the 2014 Toronto Paediatric Cancer Stage Guidelines. *Lancet Oncol*. 2020 Sep;21(9):e444-e451. doi: 10.1016/S1470-2045(20)30320-X. PMID: 32888473.

5: Ray S, Jones R, Pritchard-Jones K, Dzhuma K, van den Heuvel-Eibrink M, Tytgat G, van der Beek J, Oades G, Murphy D. Pediatric and young adult renal cell carcinoma. *Pediatr Blood Cancer*. 2020 Sep 1:e28675. doi: 10.1002/pbc.28675. Epub ahead of print. PMID: 32869954.

6: Pallin ND, Beeken RJ, Pritchard-Jones K, Charlesworth L, Woznitza N, Fisher A. Therapeutic radiographers' delivery of health behaviour change advice to those living with and beyond cancer: a qualitative study. *BMJ Open*. 2020 Aug 11;10(8):e039909. doi: 10.1136/bmjopen-2020-039909. PMID: 32788193; PMCID: PMC7422652.

7: Chitsike I, Paintsil V, Sung L, Njuguna F, Mavinkurve-Groothuis A, Kouya F, Hesselting P, Kaspers G, Afungchwi GM, Ilbawi A, Renner L, Pritchard-Jones K, Hessissen L, Molyneux E, Chagaluka G, Israels T. Working Together to Build a Better Future for Children With Cancer in Africa. *JCO Glob Oncol*. 2020 Jul;6:1076-1078. doi: 10.1200/GO.20.00170. PMID: 32673078; PMCID: PMC7392779.

8: van der Beek JN, Geller JI, de Krijger RR, Graf N, Pritchard-Jones K, Drost J, Verschuur AC, Murphy D, Ray S, Spreafico F, Dzhuma K, Littooi AS, Selle B, Tytgat GAM, van den Heuvel-Eibrink MM. Characteristics and Outcome of Children with Renal Cell Carcinoma: A Narrative Review. *Cancers (Basel)*. 2020 Jul 3;12(7):1776. doi: 10.3390/cancers12071776. PMID: 32635225; PMCID: PMC7407101.

9: Vindrola-Padros C, Ramsay AI, Perry C, Darley S, Wood VJ, Clarke CS, Hines J, Levermore C, Melnychuk M, Moore CM, Morris S, Mughal MM, Pritchard-Jones K, Shackley D, Fulop NJ. Implementing major system change in specialist cancer surgery: The role of provider networks. *J Health Serv Res Policy*. 2020 Jun 7:1355819620926553. doi: 10.1177/1355819620926553. Epub ahead of print. PMID: 32508182.

10: Sullivan M, Bouffett E, Rodriguez-Galindo C, Luna-Fineman S, Khan MS, Kearns P, Hawkins DS, Challinor J, Morrissey L, Fuchs J, Marcus K, Balduzzi A, Basset-Salom L, Caniza M, Baker JN, Kebudi R, Hessissen L, Sullivan R, Pritchard-Jones K. The COVID-19 pandemic: A rapid global response for children with cancer from SIOP, COG, SIOP-E, SIOP-PODC, IPSO, PROS, CCI, and St Jude Global. *Pediatr Blood Cancer*. 2020 Jul;67(7):e28409. doi: 10.1002/pbc.28409. Epub 2020 May 13. PMID: 32400924; PMCID: PMC7235469.



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12: Bouffet E, Challinor J, Sullivan M, Biondi A, Rodriguez-Galindo C, Pritchard-Jones K. Early advice on managing children with cancer during the COVID-19 pandemic and a call for sharing experiences. *Pediatr Blood Cancer.* 2020 Jul;67(7):e28327. doi: 10.1002/pbc.28327. Epub 2020 Apr 24. PMID: 32239747.

13: Calandrini C, Schutgens F, Oka R, Margaritis T, Candelli T, Mathijssen L, Ammerlaan C, van Ineveld RL, Derakhshan S, de Haan S, Dolman E, Lijnzaad P, Custers L, Begthel H, Kerstens HHD, Visser LL, Rookmaaker M, Verhaar M, Tytgat GAM, Kemmeren P, de Krijger RR, Al-Saadi R, Pritchard-Jones K, Kool M, Rios AC, van den Heuvel-Eibrink MM, Molenaar JJ, van Boxtel R, Holstege FCP, Clevers H, Drost J. An organoid biobank for childhood kidney cancers that captures disease and tissue heterogeneity. *Nat Commun.* 2020 Mar 11;11(1):1310. doi: 10.1038/s41467-020-15155-6. PMID: 32161258; PMCID: PMC7066173.

14: Pasqualini C, Furtwängler R, van Tinteren H, Teixeira RAP, Acha T, Howell L, Vujanic G, Godzinski J, Melchior P, Smets AM, Coulomb-L'Hermine A, Brisse H, Pritchard-Jones K, Bergeron C, de Camargo B, van den Heuvel-Eibrink MM, Graf N, Verschuur AC. Outcome of patients with stage IV high-risk Wilms tumour treated according to the SIOP2001 protocol: A report of the SIOP Renal Tumour Study Group. *Eur J Cancer.* 2020 Mar;128:38-46. doi: 10.1016/j.ejca.2020.01.001. Epub 2020 Mar 5. PMID: 32109849.

15: Watson T, Oostveen M, Rogers H, Pritchard-Jones K, Olsen Ø. The role of imaging in the initial investigation of paediatric renal tumours. *Lancet Child Adolesc Health.* 2020 Mar;4(3):232-241. doi: 10.1016/S2352-4642(19)30340-2. Epub 2020 Jan 31. PMID: 32007136.