

NephroS – National Study of Nephrotic Syndrome

ACCRUAL TO DATE: for cutoff point End of March 2017

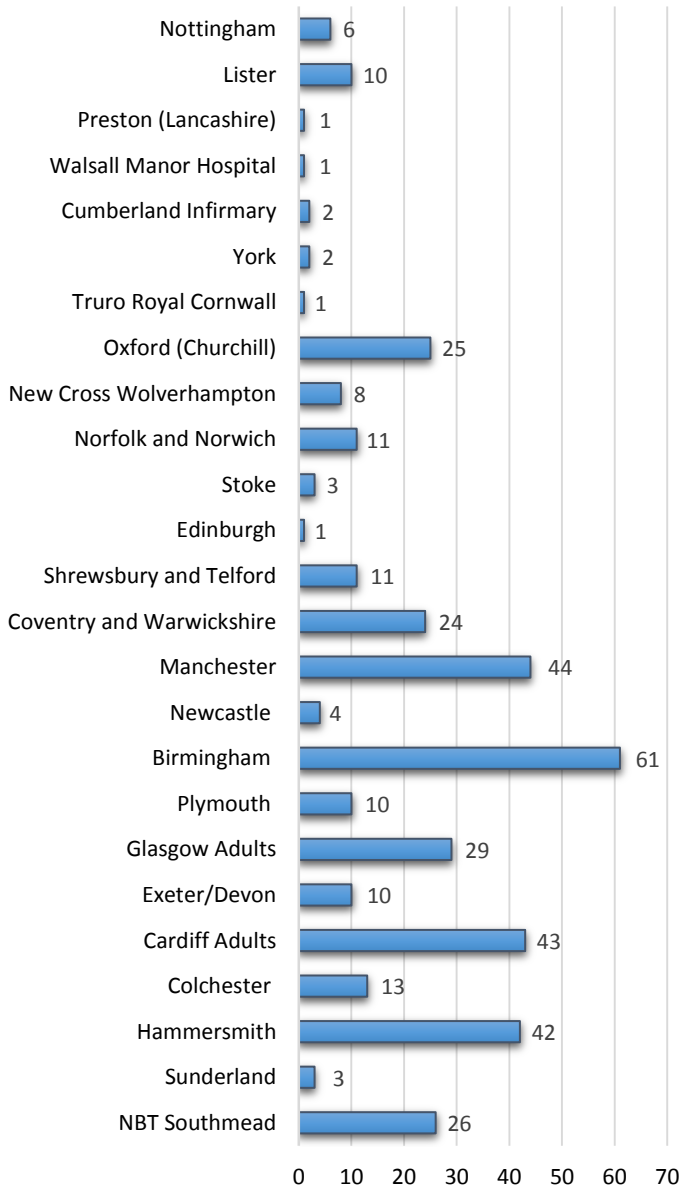
Thank you to ALL sites for all your hard work and effort for the study thus far!

Total accrual from adult sites are 391 patients. Total accrual from all children sites are 553 patients. This is a total of 944 patients recruited, only 56 patients away from a 1000!

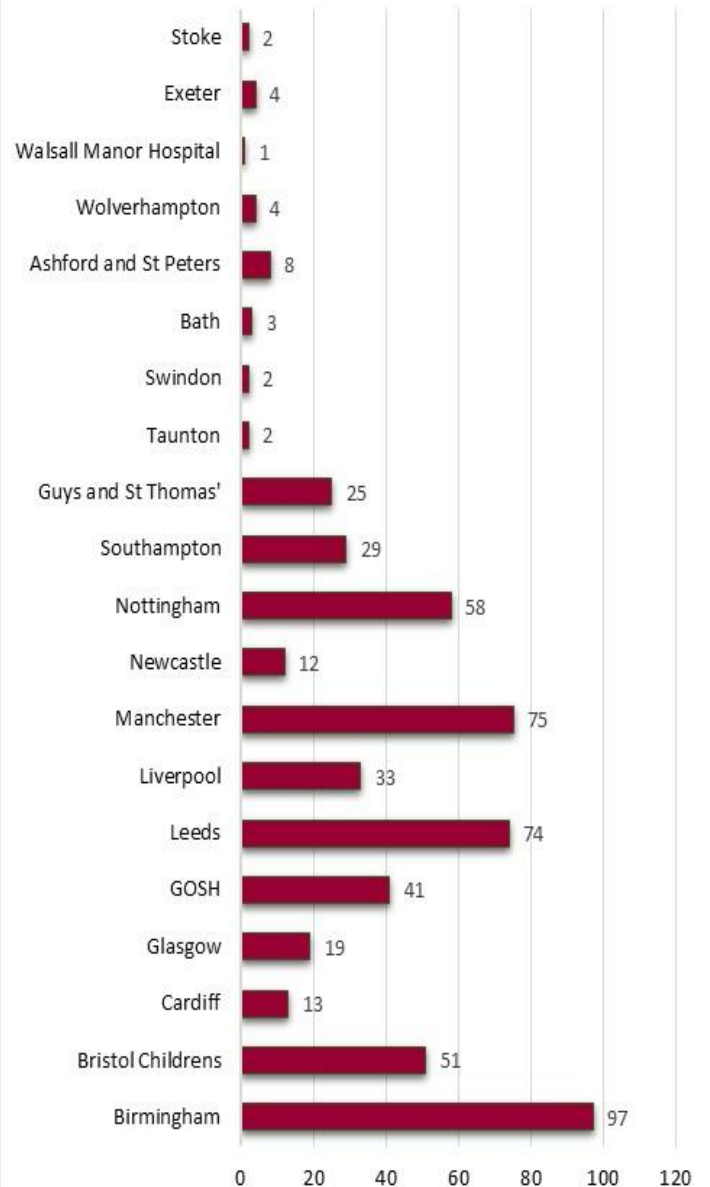
Study End Date: End of December 2019

Progress from all our collaborating sites are displayed in the graphs below. Please note that some low recruiting sites have only recently opened to recruitment.

Total accruals for adult NephroS sites (n=391)



Total accrual for child NephroS sites (n=553)



One to Watch Out for:

Dr Gavin Welsh and Dr Carl May have been asked by Kidney Research UK to speak on their behalf at the Pint of Science Festival, 16th May at 7pm.

Tickets are available from the link below:

<https://pintofscience.co.uk/event/cracking-the-kidney-disease-code#.WPqjN4Ux3RE.twitter>

They will be discussing kidney disease and the work we do as a group. Furthermore, they will be promoting this event on the Dr Phil Show on BBC Radio Bristol this Saturday (8th May) at 09:30am.

Other Announcements:

Dr Agnieszka Bierzynska will be presenting at the UK Kidney week during the Young Investigators Session. The title of her talk will be "Identification of novel NUP93 mutations in SRNS and evidence for a functional role for this protein in the regulation of podocyte biology".

Professor Moin Saleem has recently been awarded two project grants: the MRC global challenges award that will enable the NephroS study to open in 4 new international sites in India (two sites), South Africa and Egypt; and the Kids Kidney Research (KKR) award for Personalised immunomonitoring in nephrotic syndrome - towards a molecular re-classification of disease. On behalf of the Academic Renal Unit and the NephroS research team we would like to Congratulate Professor Saleem on his recent successes and thank him for all his continued efforts in supporting this research.

National Nephrotic Syndrome Patient Day 2017

Bristol Renal were delighted to be able to host the 3rd annual National Nephrotic Syndrome Patient Day at the Dorothy Hodgkin Building, School of Clinical Sciences on Wednesday, March 29th 2017. The purpose of the event was to share information with patients and their families on the current understanding of the causes of Nephrotic Syndrome and to showcase the research being undertaken into this devastating disease in Bristol. The day was sponsored by Kidney Research UK, the Nephrotic Syndrome Trust and the British Kidney Patient Association. As well as tours of the laboratories the patients and their families enjoyed talks from members of Bristol Renal and keynote lectures from Sandra Currie, Chief Executive of Kidney Research UK, Kate Creswell, Regional Advocacy Officer of the British Kidney Patient Association, and Carlie Higton who gave a very personal, emotional and uplifting patient's perspective to coping with the disease. The Organising Committee Professor Moin Saleem, Dr Gavin Welsh, Dr Maryam Afzal, Dr Liz Colby and Mrs Wendy Cook from the Nephrotic Syndrome Trust (NeST) would like to thank all who made the day such as success.

Link to talks: https://www.youtube.com/playlist?list=PLPYXF9-1-FzDJx6dLNP9_AHsUv9pyj1Jv

Response from patients and their families was inspiring with such comments as:

"Just to say thank you so much for all you did once again to make Wednesday such a success. Richard and I really enjoyed the day and are still learning, even after my having the condition for 48 years! It was good to meet so many interesting people and we found looking round the research laboratories very enlightening. What an amazing array of speakers too who were all so interesting to listen to."

"Thank you so much for a great day on Wednesday. Lucie and I both really enjoyed it. Lucie told me that she really liked to be somewhere where people "just understood". (Lucie is ten years old and travelled with her family from France for the day).



Top Left: Sandra Currie, Chief Executive of Kidney Research UK giving her talk called "Research Matters". Top Right: Carlie Highton and her father providing a personal perspective to coping with Nephrotic Syndrome. Bottom: Dr Wen Ding's interactive explanation on how healthy podocytes differ to podocytes in patients with Nephrotic Syndrome.