Latest news from ‘Nephrotic Syndrome Trust’ (NeST)
June 2016

We held a successful Nephrotic Syndrome Patient Information Day on the 16th March, at Manchester Children’s Hospital. The event was kindly organised with the help of Charlotte Bryant and Liz Colby. It was an opportunity for patients and parents to learn more about NS, sharing experiences with other families so that they do not feel alone or isolated living with the condition themselves, or caring for a child with NS. It was also an important opportunity to learn about and question the research which is being undertaken to improve outcomes for children and adults with NS.

Guest speakers included Professor Moin Saleem from Bristol Children’s Hospital, Professor Nick Webb, Dr Rachel Lennon & consultants from Manchester Children’s Hospital as well as NS patients and Nicholas Palmer from the BKPA. Everyone enjoyed the day.

One attendee commented: “The guest speakers were not only inspirational and informative, but also covered so many different aspects of Nephrotic Syndrome which we found very beneficial. I have had NS since 1969, but am still learning! It was good to hear that so much research is being done in the hope of one day finding a cure”.

The event was funded by the British Kidney Patient Association (BKPA) and Kidney Research UK (KRUK).

I hear from Liz Colby that it’s full steam ahead in the lab with the NephroS Study enrolling 50 patients a month!

NeST fundraising has also been very busy, supporting the team’s research. Many events have taken place which include concerts, raffles, pub quizzes, schoolchildren undertaking mini tough mudder; one mother completed 10k’s
in ten days; 5k colour run; tea dances and Steria fan dance – and that’s just naming a few!

Currently a husband and wife are undertaking the Lands End to John O Groats route on a tandem! A bake off, Three Peaks Challenge and a channel swim are planned in the next few weeks as well. Amazing fundraising by everyone, many of whom have ill children, or loved ones with NS, it’s truly inspirational!

A big Thank You to you all!

Wendy Cook