KIDNEY RESEARCH

The renal department at the Royal Hospital for Children (RHC), Glasgow is active in many different kinds of research, trying to answer questions that are important to our kidney patients. Though much of the research is based in Glasgow, it is often possible to offer participation to children and young people from all over Scotland through SPRUN.

Purposes/benefits of clinical research:

- 1. How we discover new treatments and prove that they are safe and effective.
- 2. How we find out new information about the conditions that we deal with.
- 3. Helps us to understand the journeys and complications that our children and families face.

CURRENT RESEARCH STUDIES

- 1. For ALL kidney patients an online survey study looking at the effect of Covid19 on mental health at different stages of the pandemic. (**The SHARE study**)
- 2. For patients on HAEMODIALYSIS a study testing a drug used in adults to treat the severe itch that can affect some patients with kidney failure. This study is looking to see if the same drug also works well in children, and whether there are any side-effects.
- 3. For patients on HAEMODIALYSIS a study testing a drug used in adults to help treat the bone disease that is caused by kidney failure. This study is looking to see if a drug can be given at the time of dialysis to help improve bone hormone levels.
- 4. For patients with a TRANSPLANT a study testing a new vaccine against shingles, already given to adult patients. This study is looking to see if the vaccine works in children, and whether the side-effects are the same in adults and children.
- 5. For patients on any kind of DIALYSIS a study looking at the emotional and psychological effects of waiting and getting a transplant. This is a questionnaire-based study. This is part 2 of a study with Glasgow contributing the most families of any centre in part 1!
- For patients with NEPHROTIC SYNDROME studies looking at new drugs that can help reduce the protein leak when steroids aren't working. There are two studies with two different drugs, to see if these medicines work as well as they do in adult patients. (The EPPIK study)
- 7. For patients with HIGH POTASSIUM a study to see if a new medicine can bring potassium levels down back to normal. This study is testing a medicine already used in adult patients, to see if the medicine works well in children.

- For patients with LUPUS NEPHRITIS a study testing a new type of medication to see if it is better than our current medicines at controlling the kidney involvement in lupus disease. (The POSTERITY study)
- 9. For patients on DIALYSIS or TRANSPLANTED a study testing blood samples given in clinic, to look for Covid-19 antibodies. (**The ISPY study**)

OUR RESEARCH

We also have our own innovation happening here! The team have a Kidney Research UK/Stoneygate innovation grant to develop a virtual reality application to help in teaching families and staff about peritoneal dialysis. This is a very exciting work in progress!

There is also a study looking back at all the children who have had E.coli haemolytic uraemic syndrome (HUS) and how they have done in adult life. This study also got some funding from Kidney Research UK.

PAST RESEARCH STUDIES

ATTOMIC – Access to transplant outcome measures in children - looking at what different factors might cause delays in patients and families being able to receive a kidney transplant

SPEAK - A study looking at psychological and social effects of having significant kidney disease as a teenager or young adult. This study helped identify factors that can protect mental health, and what may influence how well young people do in later life.

PREDNOS 1 – A study that showed that 8 weeks of steroids is just as good as 12 weeks of steroids when first treating nephrotic syndrome

PREDNOS 2 – A study looking at whether steroids stop relapses of nephrotic syndrome if given when a child has got a cold, before they relapse. Results have shown that, in the absence of proteinuria, during an intercurrent illness a short course of steroids does not stop relapse so is not beneficial.

TWIST – A study that showed that short courses of steroid at transplant were just as good as a long course of steroids.

ALXN1210-aHUS-312 – A study looking at a new drug (Ravalizumab) for the treatment of atypical HUS. This study proved that the new drug was safe and just as good as the existing drug for this very rare condition.

If you would like to know more about any of these research projects, or want to be involved at some point in the future, get in touch with the team! Ben Reynolds is the lead for research; <u>ben.reynolds@ggc.scot.nhs.uk</u>