
EMEESY

Children's Kidney Network

for the East Midlands, East of England and South Yorkshire



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**CHILDRENS
RENAL & UROLOGY UNIT**

Nottingham Children's Hospital

EMEESY

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for the East Midlands, East of England and South Yorkshire

Expert multi-professional team close to where they live!

You can find out more about our amazing network via our EMEESY website!

www.emeesykidney.nhs.uk

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Nottingham Children's Hospital

- Nephrotic syndrome (NS) is a significant diagnosis.
- 120 nephrotic patients across 18 of our centres
- 110 relapses a year- averaging around 9 a month,
- My role is to provide education and ongoing support for families dealing with NS and be their first point of contact for advice.
- The aim of this is to provide safe and consistent follow up of care during a relapse

- Majority of cases (over 90%) are primary and due to minimal change disease.
- Can be a chronic condition - significant acute and long term morbidity
- Half the children presenting with an initial episode *develop a frequently relapsing disease*
- Nephrotic syndrome is a relatively benign however mortality rates remain around 0.5 to 1%.

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- **Patients at risk of hypovolemia THINK diarrhoea, sepsis or is there inappropriate diuretic therapy?**
- **Blood is hyper-coaguable, patient at high risk of a deep vein thrombosis.**
- **Warning signs in a relapse include tummy pains, temperatures, loose stools, headaches ,cool peripherals, hypotension**
- **Network is improving safety & management but communication & education are key!**