

Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

Tel: 0191 233 6161
Fax: 0191 282 0077

The Region's Children and Young People's Kidney Team

Department of Paediatric Nephrology

Secretary to: Dr L Kerecuk Tel: 0191 2824076

The National Study of Steroid Resistant Nephrotic Syndrome in Childhood - Letter of invitation

Dear Family,

Many thanks for taking the time to read this letter. You have recently consented to information about your child's medical condition being uploaded onto a secure database known as RaDaR. This is to allow for the further study of rare kidney diseases, in this case, Steroid Resistant Nephrotic Syndrome/Focal Segmental GlomeruloSclerosis (SRNS/FSGS) in childhood.

A disease specific research group has been set up in Bristol University to study SRNS/FSGS and with permission from the RaDaR group we would like to invite you to participate in a study about SRNS/FSGS in childhood in the UK.

The principle aim of this study is understand why some children get SRNS/FSGS and how the disease causes the changes in the kidney that result in the nephrotic syndrome. We will also like to look at genes that are known to cause SRNS/FSGS and see how common they are in children in the UK with SRNS/FSGS.

At your next routine appointment with your kidney specialist they will talk to you about this study in a bit more detail and give you an information sheet that will explain what is involved if you participate.

You will be given time to chose whether you participate or not and it will not affect the level of care you receive if you do not participate.

The study has been approved by the North Somerset and South Bristol Research and Ethics Committee (09/H0106/80).

Many thanks for your time,

Yours sincerely,

Hugh McCarthy
Clinical Research Fellow
University of Bristol Academic Renal Unit

Consultants

L Kerecuk
HJ Lambert (Head)
MV Ognjanovic
Y Tse (Locum)

NS Gittins, QEH Gateshead
General paediatrician with special responsibility for paediatric nephrology

NE Moghal
(on secondment)

Senior Nurse

J Crosier
0191 2825320

Consultant psychologist

L Wirz 0191 2824051

UTI Direct Access

Nurse Consultant

S Vernon
0191 2820279

Nephrotic Syndrome/ Nurse Specialist

D Simpson
0191 2825508

Haemodialysis

Senior Nurse

D Sheriff
0191 2829190

Nurse Specialists

J Office
J Booth
J Straker
0191 2825508

Dietitians

L Boxshall
S Costello
0191 2825930

Social Worker

R Barkman
0191 2824463

Renal SpR

0191 2829566

Ward 1

0191 2825001

Day unit

0191 2826006

Directorate Manager

C Shipley
0191 2825257