

S.P.R.N.T.

Issue 3
Spring 2007

SPRUN Launches teleconferenced Nephrology / Urology / Radiology case discussion service

The SPRUN has always been committed to ensuring that staff in local teams are fully supported and equipped to look after the families from their local area themselves. Often staff in local teams are well known to the families, even before treatment commences, and understand the extended circumstances of our children and young people to a greater extent than specialists, because of their knowledge of the local area the child is growing up in or of family circumstances.

At times local teams will need the input from specialists to ensure that our children receive the most up-to-date and 'expert' opinion on their care and treatment. This does not always mean that the child will require a stay in a specialist unit or to travel long distances to see a particular clinician.

The SPRUN teleconferencing project has been launched this year to provide a service for local teams to access specialist opinion aiding their practice

in a planned programme. Local teams have always been able to access opinion and advice from specialists via letter or telephone call—this will not change.

The project allows local clinicians to discuss aspects of cases with a paediatric nephrologist, paediatric urologist and paediatric radiologist. This approach ensures that a combined opinion is given and that local teams can ask questions on the spot. Videoconferencing, using live video-streaming via a telephone line, means that both staff in the specialist centres and in local areas can see x-ray images at the same time, can discuss issues as if in the same room and agree an approach for the patient's care that is agreed by everyone—even if some are in Inverness, some in Aberdeen and some in Glasgow!

The project has set up this service for 5 local areas—Highland, Lanarkshire, Dumfries, Fife and Borders and uses expert opinion

from specialist teams from RHSC Yorkhill, RHSC Edinburgh and the Royal Aberdeen Children's Hospital.

Successful teleconferenced case discussion sessions have already taken place for several areas—where a total of 23 cases have been addressed since February 2007.

The project is an excellent example of the benefits networking can have for clinical practice. As with any new initiative the project has presented challenges along the way—the SPRUN are grateful to the many clinicians who have taken part and continue to help us work through the issues to make the most of this opportunity.

If you would like more information on this initiative please contact network Manager Derrick Pearce via email derrick.Pearce@yorkhill.scot.nhs.uk or phone 0141 201 0068. A full timetable of the teleconference case discussion dates for each area is available along with information on who the local co-ordinators are.

Calling all nurses.....

This Spring the SPRUN is hosting a networking event for nurses.

We hear regularly from families and professionals about the key role nurses play in delivering care to our families.

Nurses working in the community, in inpatient paediatric units across the country and in specialist roles all have an influence on and a responsibility for the delivery of our services.

The SPRUN wants to give you the chance to get involved. The

networking event, organised by Ursula Monahan, Renal Unit Sister at Yorkhill and Nicola Crawford, CCN in Stranraer, will include talks from your colleagues on their roles in the network and a chance for you to explore what the network can do for you!

Flyers for the event have been sent out to all our nursing contacts. Please return these to the network office to reserve your place.

SPRUN Nurses Group Event

**Royal Hotel, Bridge of Allan,
Stirling**

Monday 4th June 2007

10.30—3.30



SCOTTISH PAEDIATRIC RENAL NETWORK TIMES



SPRUN Pharmacists' Group moves forward



SPRUN PHARMACISTS Seminar—

November 2006

St Johnstone football club in Perth was the venue for our first Seminar for Pharmacists in November of last year. The event organised by Specialist Paediatric Renal Pharmacist Angela Lamb, and funded by Kidney Kids Scotland, allowed paediatric pharmacists from across Scotland to come together for an afternoon to discuss issues related to paediatric renal pharmacy.

At the session Angela gave a presentation on the Patient Held Renal Medication Booklet she has designed. The booklet is intended to ensure that children, young people and their families have ownership for their own medicines and can keep an easy personal record of their drug treatment. Angela also presented some findings from an audit of the use of the booklet—focussing specifically on the thoughts of our families who have used the booklet.

Sister Ursula Monachan, Ward Manager of the Yorkhill Renal Unit, was on hand to speak about her experience of the booklet with patients from the nurses' perspective.

The pharmacists attending the meeting agreed that the booklet should be used across the country and are planning pilots of its use in Ayrshire & Arran and Lanarkshire starting in Summer 2007. Kidney Kids Scotland has agreed to fund the pilot and future use of the booklets.

The pharmacists Group have also decided to come together twice a year for training and education, and to network together to further develop pharmacy services to our renal and urology children throughout the country.

The next meeting of the SPRUN Pharmacists Group will be on 30th April 2007 from 10am until 2.30 pm in the Royal Hotel Bridge of

Allan. Details and booking forms have been sent to all SPRUN Pharmacists' Group members.

For more information or to join the SPRUN Pharmacists' Group please email

Angela Lamb
angela.lamb@yorkhill.scot.nhs.uk
 or
 Derrick Pearce
derrick.Pearce@yorkhill.scot.nhs.uk

SPRUN PHARMACISTS GROUP

Training and Education Session

Pharmacy in Renal Transplantation and Nephrotic Syndrome

Monday 30th April 2007

10.30am—2.30-pm

Royal Hotel Bridge of Allan,
Stirling

NEW UROLOGY CLINIC FOR HIGHLAND

Tuesday 27th February 2007 saw the launch of a new joint urology clinic at Raigmore Hospital in Inverness.

The clinic, which will take place quarterly, allows children and young people from the Highland health board area to be seen by Mr Chris Driver, Consultant Paediatric Urologist from the Royal Aberdeen Children's Hospital, closer to their own homes.

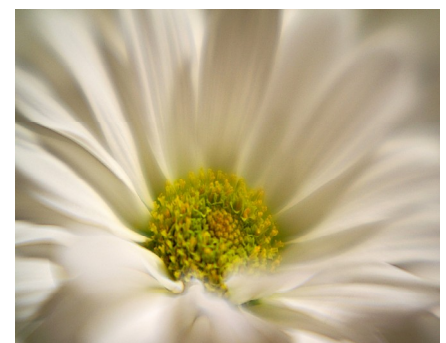
The clinics will mean that fewer children from the Highland area are required to travel to Aberdeen for their Urology clinic

appointments. Paediatric Urological surgery will still be carried out in Aberdeen but pre-surgery and post-operative clinic appointments can now be attended in Highland.

Dr Alan Webb, Consultant Paediatrician in Inverness will support the families locally in close liaison with Mr Driver.

A total of 16 patients were seen at the first of these clinics on 27th February 2007, which was followed by a videoconferenced post-clinic meeting.

The SPRUN congratulate Mr Driver and Dr Webb on setting up this clinic and are grateful to the staff in Highland for their assistance. Thanks also to Kidney Kids Scotland for their invaluable financial support for this venture.



SCOTTISH PAEDIATRIC RENAL NETWORK TIMES



SPRUN Families Groups

"We will have our children ' young people and families at the centre of everything we do "has always been the principle aim of the Scottish Paediatric Renal Urology Network.

Our families deserve the best possible care regardless of where they are and what condition they have. In order to ensure that the renal and urology service for children and young people is developed in line with what the users of our service expect the SPRUN is setting up three **SPRUN Families Groups**.

There will be a SPRUN Families Group in each region of the country (the North — around the Aberdeen centre, the South and East—around the Edinburgh and Tayside centres, and the West— around the Glasgow centre), but families will be able to attend any one of the get togethers and do not have to be part of a particular group. We hope that the groups will come together 2 or 3 times a year in each region.

The purpose of these groups is really up to the families involved but we hope that they will be both a chance for families to come together and meet each other, and an opportunity for network members to have feedback on

the service and hear ideas for how the service can be made better.

The first SPRUN families group met in Glasgow in November 2006. A group of around 7 parents and children came together with our parent member Rebecca, supporters from Kidney Kids Scotland and Network Manager Derrick for a lunch and a chat.

Families attending had a range of experiences of the services across Scotland. The families were keen that the get togethers should not be about a 'moaning session' or a 'complaints group' - there was real enthusiasm to help improve services for the future. Of course there are aspects of the service that are not perfect and we had the chance to hear about these too.

The families' overwhelming feeling was that individuals working in the service do a great job but that sometimes the way their service is organised makes it very hard for families — but that this could be changed if everyone works together. The first steps towards this must be about families getting to know each other and speaking up about what they really think... Good or bad!

If you think you would like to be put in touch with other families who have a renal or urology condition please get in touch with us at the numbers opposite.



You can have details of other families you can link with, details of the support Kidney Kids Scotland can provide and get information about coming along to a Families Group Get Together. You can decide what you would like and there is no pressure to get involved.

We have two Families Group Get Togethers Planned for the next few months. If you would like to come along to either or both of these just give us a phone so we know to expect you.

SPRUN Families Group Get Togethers

Monday 28th May 2007

**11am—3.00, Gather in Glasgow
Ruthven Lane, Glasgow**

Saturday 23rd June 2007

11am—3.00pm

Elgin Library, Elgin

For more information:

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SCOTTISH PAEDIATRIC RENAL NETWORK TIMES



Bits and Pieces!

SPRUN Annual Report

Each year the SPRUN is expected to produce a report for NHS National Services Division. The report, which will be published in June, will set out what the network plans to achieve in the current year and report on what we have already achieved in the past year.

The SPRUN can be proud of the huge amount of good work going on and of achievements in the past year. We will keep you informed via SPRNT, this newsletter, when the Annual Report is completed. Copies will be made available for network members and the public as soon as the report is published.

CONGRATULATIONS!!

Since our last Edition of SPRNT there have been some happy developments for SPRUN members...

Amita Sharma, Consultant Paediatrician in Paisley RAH gave birth to a baby girl. Mum and daughter are both doing well!

Janie Donnan (nee McEwan), Clinical Psychologist based at RHSC Yorkhill was married at the end of 2006!

Angela Ayoma, CCN in Highland, has moved on to a new job in Lancashire. Good luck—you will be missed!

Best wishes to you all!

Number Crunching...

We are often asked **how many children and young people there are in Scotland who have a renal or urological condition**. The answer is very difficult to give given that there are upwards of 30 different conditions! We are a step closer, however. Thanks to staff at NHS Information Services Division we now have information on the number of admission to an inpatient children's ward there were in Scotland for any the renal and urology conditions we know about. In the last 5 years this has been in the region of **5000 episodes per year**.

We know very little at the moment about the numbers of children and young people with renal and urology conditions seen in outpatient settings but we are working on finding this out.

We continue to work with information services colleagues to find out how many individual children and young people there are... Watch this space!

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'LINK' NEPHROLOGISTS

A team of 5 Consultant Paediatric Nephrologists based at RHSC Yorkhill provide the paediatric nephrology service for Scotland—that's 14 health board areas. Of course the team reply on colleagues from all disciplines to do this but in a bid to manage their workload more sensibly and improve communication there are now

named 'link' nephrologists for each local area. Each of the 5 Nephrologists is now attached to a local area as their 'link'. Information about this new system has been sent out to all paediatricians for comment. If you want any further information contact SPRUN Lead Clinician David Hughes.



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