



# Newsletter



[www.childrenskidneynottingham.nhs.uk](http://www.childrenskidneynottingham.nhs.uk)

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## Hello...

Spring  
2009

Welcome to our Spring 2009 newsletter. We're full of the joys of spring and bringing you lots of news and information about our unit.

We know we keep saying it, but this newsletter is yours and we would really like you to contribute to it. If you don't want to write anything, that's ok, but any feedback would be appreciated.

We would like to send the newsletter by email, it saves on trees, NHS costs, and your time. Please tell us your email address if you would like us to contact you by email.

Enclosed with this Newsletter is a questionnaire about our service. Please return it in the envelope provided; your views are really important to us! (If you feel you are not able to do this, it will not affect your child's treatment.)

Don't miss out on this year's holidays for young people. If your child would like to go, return the enclosed form by the 8<sup>th</sup> May.

Have a great summer,

[donna.hilton@nuh.nhs.uk](mailto:donna.hilton@nuh.nhs.uk)

[shelley.jepson@nuh.nhs.uk](mailto:shelley.jepson@nuh.nhs.uk)



Best wishes

Shelley & Donna

## Renal Patient View...

Renal Patient View is an on-line patient information system which is available to you. If you have access to a computer you can see your child's blood results on the site, from any computer with internet access. 25 families have now signed up to Renal Patient View and have found it very useful.

To find out more log on to [www.renalpatientview.org](http://www.renalpatientview.org)

## Welcome...

Lynn Brand, our new receptionist



Staff nurses:

Caroline, Julie, Kerry-Ann, Monique, Donna.

Welcome back from maternity leave: Kate

## Goodbye..

Linda Benson: ward receptionist has left us after 13 years on Lambley and E17. Linda has gone to work round the corner on PICU so we will hopefully still see her from time to time. We wish her well...

Stephanie Joyner: Steph worked with us for many years, much of the time on nights. She has left to work in the community.

Vikki Brewer is leaving us go back to PICU.

Ben Harvey has moved to Leicester.

Best wishes to you all, you will be missed!



# Kidney Unit News...



## FP10 Prescriptions...

Since moving to the Queens Medical Centre we can now issue an FP 10 prescription to allow you to collect your medicines direct from your chemist rather than the hospital or GP.

If you have no problems getting your medication from your GP please continue to do so.

For those of you who have difficulties then please ask for a FP10 at clinic or telephone for one to be posted to you.

Please allow time for postage and getting the supply at the chemist.

The prescription can be taken to the chemist within a month's time frame.

When you take the prescription to the chemist please do not expect to receive your medicines immediately they may take a few days to arrive.

Medications that can be prescribed on an FP10 are:

**TACROLIMUS**

**MYCOPHENOLATE**

**PREDNISOLONE**

**SEVALAMER**

**ERYTHROPOETIN (EPO)**

For any more information please contact Kim Helm on 0115 9707409

*Kim Helm*

*(kim.helm@nuh.nhs.uk)*

## Transplant Patients...

**STOP PRESS!!!! STOP PRESS!!!**

**DATE FOR YOUR DIARY -**

**JULY 30<sup>th</sup> to AUGUST 2<sup>nd</sup> 2009**

**BRITISH TRANSPLANT GAMES**

**VENUE : COVENTRY.**

**ANYONE INTERESTED PLEASE CONTACT KIM HELM 0115 9707409**

**YOU WILL NEED TO APPLY BY MAY SO PLEASE LET ME KNOW BY END OF APRIL.**

**FLY the FLAG FOR YOUR TRANSPLANT UNIT, MAKE FRIENDS AND HAVE FUN!!!**

# Kidney Unit News...

## Childrens Clinic Update

As you may already be aware Children's Clinic has now transferred from the City campus to QMC.

There are now two children's clinics at QMC campus; the existing children's outpatients is now called **CLINIC EAST**.

The newly refurbished clinic (situated in the old dermatology clinic) is now called **CLINIC SOUTH**.

The majority of the renal clinics will be held in **Clinic South**. Please bear with us whilst we settle in to our new surroundings.

There is a comments book in Clinic South if anybody has any constructive feedback or suggestions about the new area.

There are temporary signs in place at present. These will stay in place until the permanent signs are changed when the fire regulations have been updated.

Thank you all for your patience during this transition period.

*Roy Connell*

## Babysitting Service...

We are about to re-launch our babysitting service for children on dialysis.

This involves staff from the unit babysitting for you at home.

Look out for more details in Children's Clinic or on our Website.

If you are interested please speak to Heidi, Suzanne or your Nurse.

## Competition Time...

**Recipes for a Renal Diet**

**Enjoy cooking?**

**Creative in producing good food that is good for your kidney?**

**Enter our competition and win the widely acclaimed "Nora's Dinners" cookbook.**

**What do you have to do?**

**Send your favourite and healthiest recipe to our dieticians Pearl or Alison.**

**They will decide which has the best content and is most appetising.**

**The best recipes will be put on our website to be a resource for others looking for culinary inspiration!**

# Your Space...

By Laura McClean

Hello my name is Laura I am 17 years old and I live in Rotherham. I was born with kidney failure but was diagnosed at 8 years old. For a lot of years I've been on medication, which has been helping my kidneys not to deteriorate even more.

I only started CAPD dialysis June 08, which was very hard to cope with, because I've not been used to being restricted. Eventually I got use to it. This dialysis was treated at home as well, which was a lot better being around my family so they could help and support me. I had to do 3 bag exchanges through the day. 1st one at 9am, 2nd one at 3pm, and the last one was at night at 9pm. Then 6 months later I was transferred to PD Home choice dialysis, which is where you dialyse over night on a machine. I did one called opti-choice, which is a lot better option for a person of my age. You're not as restricted as much as you would if you did home choice. With home choice you would start on the machine at about 6pm at night till 6am in the morning.

With the one I was doing, opti-choice, I did a cycle of 1 drain, 1 fill, and 1 dwell at about 6pm. This lasted about 20-30 mins approx. Then you would disconnect and come back on to the machine again at 10pm and then go through 8 cycles in 8 hours. The dialysing would finish approx about 6am-6.30am in the morning. That was my daily routine 7 days a week. I was on dialysis for 8 months.

Then I got transferred on to the kidney waiting list for a transplant. I was only on the waiting list for 4 weeks. Then on 24/02/09 at 2am in the morning I got a phone call telling me that there is a kidney waiting for me. I was so shocked and very emotional but happy and so scared at the same time. I then quickly got a bag together and set straight off to QMC Nottingham with my mum and dad.

I got to Nottingham at 4am and was transferred to E17 the renal ward in QMC. I got checked out straight away. The basics weight, height, BP, Temperature and then lots of bloods. These bloods made sure that this kidney was a right match for me. The bloods then got transferred to Sheffield to be analysed.

Now at this time it was a waiting game. It was so nerve racking for the whole family including myself. Time passed by and a soon as I knew it was 12pm. My blood results would get transferred to the QMC up to the ward so the doctors and nurses would get told over the phone. At 12pm I had a heart scan to make sure my heart was working well. Then at 12.30pm the phone rang. The nurse ran out of the room to answer the phone. By that time we all knew it was my blood results. Fingers crossed we all hoped it was all okay to go ahead with the transplant. Then 5 mins later the nurse came in with a smile on her face and said yes it all fine to go ahead with the transplant. We all smiled and started get emotional, because this was it.

The bestest thing in my whole life was going to happen!

Next thing I knew I was told to put a theatre gown on, and walked down to the theatres with my mum and dad and the nurse. Nerves were kicking in by then a really lot for me. I was so scared and emotional. Also my parents were too. I knew I was in their care I was going to be fine. Next thing I was laying in the anaesthetic room with my dad holding my hand telling me I will be okay. By that time I was getting drowsy by the anaesthetic going through my canula and then I couldn't remember a thing. At 5.30pm I was laying in my bed in paediatric intensive care unit so drowsy and in a bit of pain, but not as much as I thought I would be in because of the morphine which was going through me to ease my pain.

I was coping well and felt better as days went by. I was in PICU for 48 hours, then was transferred to E17 into a cubical with my mum. I was getting a lot better each day passed by. I was in hospital for 10 days other all. I was really shocked to think I was in a such a little time to say I had a major operation. I am coping well now I feel fantastic and looking really well. I'm just a bit swollen due to the high steroids I'm on daily.

I take tablets now for the rest of my life, which is a lot better than having to go through dialysis everyday.

I have to take a number of different tablets such as anti-rejections. Also I have to come for regular check-ups twice a week, to make sure the kidney is working good and healthy. I go up for a ward review on Mondays and then have my regular check-up in clinic Thursdays.

So that's my life and overall now I'm enjoying life it is great!

Hope you enjoyed reading my life about being on dialysis up to transplantation.

Thanks Laura x



# And the Truth of the Matter is...

*Message from  
the Professor*

## View from the Bridge...

March 16<sup>th</sup> saw another major part of the transfer of the unit from the City to the Queens campus when the clinics opened in Children's Clinic South. This is a new environment and we know the space is limited at times in the waiting area. However we hope to develop the area as much as possible to make it child, young person and family friendly.

We are also aware of the congestion at times on E17 at times with the lack of space for day case and ward attendees. This has been a major focus of our team discussions and we are hoping to develop a day case area over the next 12 months. We have received a large legacy from a Will to start the development. We thank all those who have donated monies to the Kinder Appeal (Children's Renal Fund). If any one wants fund raising information or has an idea for raising monies then do get in contact.

The team are always keen to offer as much support as we can to families and we certainly appreciate how important breaks and holidays are to families. We spend money each year to support children with chronic kidney disease at Center Parcs and activity holidays are held for other children and sometimes siblings. Please contact a member of the team for details.

We are **KEEN** to hear your views and input about the services we provide, information materials and any ideas in general. Do visit our website at [www.childrenskidneynottingham.nhs.uk](http://www.childrenskidneynottingham.nhs.uk).

We are holding our Renal Family Forum on **Saturday 16<sup>th</sup> May** at the Postgraduate Centre on the QMC campus. Time 10.30 am to 3 pm with lunch included. See flyer for signing up. Hope to see you there.

Ever onward!

*Prof Alan R Watson*





# Team Spotlight...

## Dorro Hackett - Youth Development Worker

It's not all Uno playing & Mario Kart for a Youth Development Worker (although skills in these areas are helpful & do require lots of practice!)

My role is split into different parts and I am required to do a wide variety of things. I am here to provide non-medical support for young people on the ward, dialysis unit, at home and through the transfer to adult services.

This support can be in many different formats; whether it is away from the ward in our well-equipped Youth Room, spending time with a person on the ward or away from the hospital on day trips, residentials, or at home.

Young people choose to take part in Youth Work activities and we aim to develop programmes that meet their needs and interests.

I recently accompanied eight young people to Center Parcs where they took part in a number of activities relating to transition to adult services. It was a great weekend and really good to get to know young people in a different environment.

Earlier this year I started the Youth Achievement Award scheme with young people in the dialysis unit. This nationally recognised accreditation can help develop skills in planning, group work, peer support and budgeting.

I would love to hear from anybody who would be interested in finding out more about the Youth Service and the programmes that we offer patients, as well as those of you who have any ideas for projects etc and would like to get involved.

I can be contacted on

**0115 970 9421**

or by email:

**dorro.hackett@nuh.nhs.uk**

Now...back to the PS3!

*If anyone has any ideas for fundraising or would like to make any donations, please contact Judith Hayes on 0115 9709420*

# Donations...

A HUGE thank you to all those who have recently made contributions to our charity

## The Kinder Appeal

Donations to the Kinder Appeal September 2008 - March 2009

Liam White

Morley family

Pearl Pugh

Moorgreen Delivery Centre

Shirley Jacques workplace

Dene Lindley

Mr & Mrs Basak

Shirley Jacques workplace

Mark & Sarah Bawden

Sophie Ashmore & family

Ginger's Hair & Beauty Studio

Mrs Brenda Moull

Helena Romanes School, Essex

Mrs Pam Fox, Inner Wheel

Club of Dunmow, Essex

Estate of Sybil Jessie Ditchburn

The Freemasons Grand Charity

The Sir Robert Gooch Fund

Julian Brocksopp

Lowndes family - in memory of Donald Lowndes

# Holidays for Young People...

Summer is coming and we have got Holidays planned...

The BKPA have once again funded 2 residential holidays for young people this summer, **Fairthorne Manor, Southampton, 3<sup>rd</sup> - 7<sup>th</sup> August** and **UK Sailing Academy, Isle of Wight 10<sup>th</sup> -14<sup>th</sup> August**.

**Fairthorne Manor** is a fantastic outdoor adventure site offering a range of outdoor adventure activities from abseiling to kayaking and aerial runway to raft building. This holiday is aimed at patients aged 9 - 13 years.

**The UK Sailing Academy** specialises in introducing people of all ages to the great outdoors through the medium of water sports. Whatever your ability or previous experience, there will be something for you! This holiday is aimed at patients aged 13 - 16 years.

**Register your interest ASAP as there are only 10 places available for each holiday! Fill in the form enclosed with this Newsletter.**



NUH Youth Service  
E Floor, East Block, QMC Campus  
Derby Road  
Nottingham. NG7 2UH

PHONE: 0115 970 9421  
EMAIL:  
NUHYOUTHSERVICE@NUH.N  
HS.UK

If you would like any further information on the Hospital Youth Service, please get in touch!

**DON'T FORGET  
OUR WEEKLY  
YOUTH CLUB!**

MON - 7-9pm

WEDS - 7-9:30pm

### Summer Holidays...

As well as the Renal Holidays in the summer, the Youth Service will also be planning some day trips for you to get involved with.

The final programme is yet to be confirmed but the trips are likely to take place every Friday during the summer holidays.

We will send out details nearer the time.

### Any Ideas?

If any of you have any ideas for trips and events, fundraising ideas or have any stories/experiences that you would like to share, please get in touch...we would love to hear from you!

[Nuhyouthservice@nuh.nhs.uk](mailto:Nuhyouthservice@nuh.nhs.uk)

# Youth Service News...

The Youth Service Base was officially launched at QMC in November 2008. The new space is much bigger than we had at the City Hospital and is jammed packed full of equipment such as a 50" Plasma TV, PS3, Nintendo Wii, games, DVD's, Leather Sofa and chill-out area, arts & crafts equipment, kitchen area and Internet point. Daily drop-in sessions take place every weekday afternoon for inpatients and so far over 80 different young people have been in since the launch.

The Base was generously sponsored by the NUH Charity, who provided the funding for the maintenance work and all the equipment.

### National Award-Winning Service!

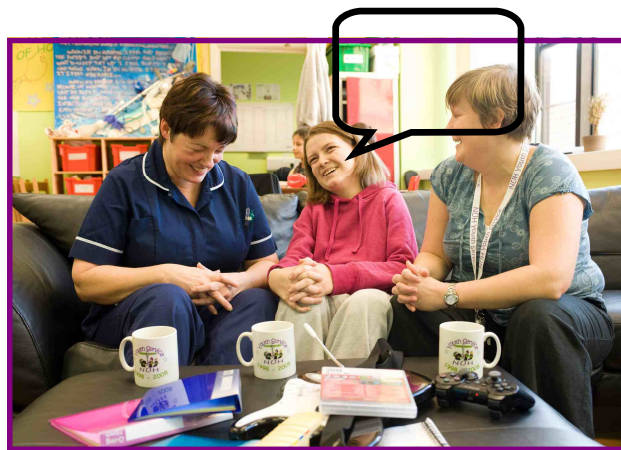
At the back end of last year the Youth Service were also celebrating winning TWO National Awards!

We picked up the Children & Young People's Services Awards - Youth Work Award and the Gillette Clubs for Young People - Health Youth Club of the Year Award.

Both were outstanding achievements of which we are very proud!



Pictured here are members of the Youth Work Team receiving an Award from former Blue Peter Presenter Peter Duncan.



What is Squid, Renal Patient, saying to make Kim pull a face like that???

Best caption will win a prize!

Email your answer to: [NUHyouthservice@nuh.nhs.uk](mailto:NUHyouthservice@nuh.nhs.uk)