

# Paediatric rheumatology newsletter

ISSUE ONE

## Welcome to the first paediatric rheumatology newsletter...

The paediatric rheumatology team at Southampton is pleased to see our service growing and improving rapidly. We are keen to update you all on our changes and hope these newsletters will be a regular item throughout the year for you to pick up in the clinic.

GET INVOLVED!

If you would like to be involved in the newsletter or have ideas for anything you would like to see in it please contact Sarah Hartfree, specialist nurse.



## Ultrasound scanner

You may have noticed we now have an ultrasound scanner in clinic twice a month, managed by Sandra Gadola, rheumatology ultrasound technician. Having Sandra in clinic means we can review, examine and determine treatments much quicker.

It also means patients don't have to return to hospital for their scan appointment or have a clinic

appointment for review of the scan. If you notify us of flares of activity using the patient line number we can make sure your child has an ultrasound scan very quickly in clinic.



## Patient education

We have now started running sessions to improve child and parent education within paediatric rheumatology. Not only do the sessions enable children and parents to learn more about their condition they also give you a chance to meet other children and families with similar problems.

So far the team have run sessions on pain management and on the drug Methotrexate.

Although there are still improvements to be made, the sessions were very positive in helping our patients and families to learn.

### Future education sessions will include:

- Physiotherapy input – 25 February 2012
- Psychological input
- Juvenile idiopathic arthritis (JIA) – different types

To view all proposed teaching sessions go to [www.uhs.nhs.uk/childrensrheumatology](http://www.uhs.nhs.uk/childrensrheumatology)

Email Sarah on [s.hartfree@nhs.net](mailto:s.hartfree@nhs.net) or call **07760 158 924** to book your place.

## Research projects

The paediatric rheumatology team is about to start various research projects that you may be asked to become involved with. As the projects progress we will update you with any findings and outcomes.

The studies we are involved in are:

- Sycamore Study - Uveitis
- Methotrexate Study
- Lupus Co-hort Study
- Biologics Survey
- Eterncept BSPAR Register



## Paediatric rheumatology web pages

We are currently developing some web pages for paediatric rheumatology on the UHS website, at [www.uhs.nhs.uk/childrensrheumatology](http://www.uhs.nhs.uk/childrensrheumatology)

These will include information on what to expect at a paediatric rheumatology clinic, links to rheumatology groups, patient education sessions and patient experiences.

**If you would like to be involved in the website and help us improve and expand it please contact us.**



## Fundraising

It has been great to get funding this year for our annual Christmas event, held at the Berry Theatre, with great thanks to Medco, Healthcare at Home and Starlight for their kind donations to ensure this event could happen.

As a team our passion is to make the service bigger, helping to provide our children and families with a better service.

**If you are interested in helping to raise money for the paediatric rheumatology fund we would be very grateful for your input or suggestions.**



On 26 May 2012 we will be hosting a summer BBQ and would love all families involved for a day of fun and fundraising.

## Future plans

Our aim is always to move forward with our service and of course increase our resources within it. Initially we would like to increase the availability of our ultrasound service to weekly and improve our therapy access in occupational therapy and physiotherapy.

If you have any views on our future please feel free to inform the team.

We would like to thank you all for supporting our service and hope you are happy with the positive changes.

Lastly, merry Christmas and a happy new year from the paediatric rheumatology team.

## Parents' forum

We are pleased to announce that we now have a parents' forum to help parents/guardians form a social network to support and discuss any matters linked with their child's illness.

We encourage parents to use this link to share their concerns, worries or expertise to help others.

To find out more, or join, visit [www.uhs.nhs.uk/childrensrheumatology](http://www.uhs.nhs.uk/childrensrheumatology) and follow the link for the parent forum.

## Transition to adult care

We are working to improve the process for patients moving from children's to adult care.

This is something the Department of Health are keen to improve across the country.

In future, if your child is 11 or above they will have an appointment to attend a transition clinic with Sarah, to guide them through the process.

We are very lucky to have Dr Davidson involved within the children's team, as he continues to see our patients once they have made the transition to young adult care.

## Contacting the team

We have tried to improve patient contact by introducing the patient line mobile telephone number

**07760 158924**

You can also now contact Sarah by email [s.hartfree@nhs.net](mailto:s.hartfree@nhs.net)

We hope you have seen an improvement in patient query contacts. Please let us know if we can improve this service further.