



Congenital Adrenal Hyperplasia Clinic
<http://www.cahisus.co.uk>



Great Ormond Street Hospital for Children

NHS Foundation Trust

DEPARTMENT OF ENDOCRINOLOGY

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CAH GREAT ORMOND STREET PARENT AND PATIENT GROUP NEWSLETTER AUGUST 2013

Dear All

Hope you are all enjoying the Summer and the sunshine.

Apologies for the lateness of this newsletter we have been waiting for updates on several important items regarding the services at GOSH.

All change at GOSH

We are delighted to welcome two specialised endocrine paediatric nurses to our team. Both nurses are well experienced in adrenal issues and we look forward to them starting with us in the next couple of months. This will give you a named contact and telephone number which should improve access.

The planned changes regarding Kingfisher Ward are still in progress and we hope to have a full update in our meeting. What is likely to happen is that Kingfisher will continue as a 'Planned Investigation Unit' but will be open 7 days a week instead of the current 5 days. What this means is that for profiles in particular we will be able to offer weekend profiles starting either Saturday or Sunday mornings. Radiology will also be working 7 days too so that hand x-rays and bone density measurements will be done at weekends as well. This will allow us to do more profiles of course but also give you more flexibility in when you want them done. So when we are talking in clinic about booking a profile you will need to ask us for a weekend slot if you want one until we all get used to weekend profiles!!

Next Meeting

Yes we know not even got back to school and we are thinking about Christmas!!

The next meeting will be held on Saturday November 9th at the Institute of Child Health at 1:45 pm and we look forward to seeing you all there, we hope to be able to give out invitations to the Christmas Party. Paul will have a supply of sport bands for sale.

We have a very full programme planned and hope to introduce a very exciting new venture designed by one of our parents, for which we will need our families' feedback on.

We will discuss cortisol clearance, the variance and what this means. We are delighted to have Richard Jackman and his mum Alice, tell us of their experiences and what happens when you have very high cortisol levels.

One of the other areas that we will be covering is disability and discrimination and we hope to have an expert on this at the meeting to take us through the legal bits. The person we have in mind is really good and keeps it simple but factually correct so it should be a really useful session. The areas that we will cover will include schooling and responsibilities of schools right through to employment law and discrimination based on disability in the work place.

Consultant Paediatric Endocrinologists: Professor Peter Hindmarsh, Professor Mehul Dattani,
Dr Caroline Brain, Dr Helen Spoudeas, Dr Catherine Peters

Department of Endocrinology – Adrenal Clinic

Questions and Answers

One thing we get through our email account is a lot of questions about CAH. These take many forms but nearly all raise some practical issue. We thought it would be a good idea to start sharing these so we have grouped the questions into subjects and the first set of Questions and Answers are on profiling and is now available on the Articles page on our website.

Do have a look and if you like this idea let us know. Even better send us a question and we can then add that one!!

Useful suggestions

Finally, it is still summer holidays so if you are traveling make sure you are well stocked up with meds and that the emergency kits are up to date. Don't forget our travel leaflets on the web www.cahisus.co.uk.

Getting ready for back to school? Again make sure meds for school are all in stock and date and that the emergency kits are still in date after the long break.

For new starters our Nursery or School Plans are very helpful and liked by Nursery and School staff so do go on line and download them.



Fundraising

As discussed at the last meeting, we are hoping to do several research studies and we are extremely grateful to the families that have done fundraising for us. A very big thank you to Bernie for her wonderful donation and also to Nick and Linda Woodcraft for their brilliant donation, Nick still has the gruelling Perranporth Surf Challenge Triathlon which is scheduled to take place on Sunday 8th September 2013. For those would like to sponsor Nick on this, donations can be made on line, <https://www.justgiving.com/nickwoodcraft>

We really do appreciate the input our parents are putting into helping us with our research into CAH. Paul has done a wonderful job in designing, supplying and selling sports bands at our meetings, we are very grateful for his continued support.

Thank you

Our thanks to Jacqui Mayes who is a Nutritional Therapist and gave a very interesting talk on blood glucose and cortisol at our last meeting. For those who missed it, please see a summary of her talk on the Articles page on our website.

A big thank you to Amanda for redesigning our new Adrenal Insufficiency Card. We are delighted with the improvements and we will have a supply for our meeting.

Also thank you to everyone for your continued support and for coming along to our meetings. We look forward to seeing you all in November.

With very best wishes

Professor Peter Hindmarsh