



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

Great Ormond Street Hospital for Children **NHS**  
NHS Trust

DEPARTMENT OF ENDOCRINOLOGY



## PARENT AND PATIENT GROUP NEWSLETTER NOVEMBER 2011

### Our Meeting 8<sup>th</sup> October 2011

A big thank you from all our team at GOSH to all those who attended our group support meeting last month. It was most encouraging to see such a good attendance. We have been overwhelmed with your kind comments and it is most gratifying to our team that we are making a difference in improving the care to all our families with CAH. For those who couldn't make the meeting, we hope that you can come to our next meeting in April 2012, (we hope to announce the date soon).

A big thanks to Dr John Honour for his most interesting talk, 'All you want to know about steroids but were to afraid to ask', which was not only extremely informative but also injected with clever humour. He has donated his slides to the group, so we hope to put these into a leaflet for all to read and use for reference. The coverage of steroid use in sport was fascinating as was his rendition of the formation of the different sexes!

John was delighted to meet some of the parents and the patients, having seen only 'bits' of them or their children over the years and I think often we tend not to really appreciate the hard and incredibly important work that goes on in the laboratories! John has always had a keen interest in CAH and has been involved in many studies and the development of better and more accurate assays to measure all the hormone levels we all look at.

Also thank you to Dr Rebecca Sweet, who is part of the psychology team at GOSH, for her talk on 'CAH and The Family'. We have picked up on some of the concerns raised and hope to cover these in the future and be able to give you all feedback which we hope will prove helpful.

Thanks to Abigail Atterbury our new CAH nurse and to Victor Mead our Auxologist for coming along too.

### Emergency Care

Many of you will remember, as you kindly filled in our detailed questionnaire, we are working hard to improve emergency care. We have produced a leaflet showing the results of the survey, if anyone would like a copy, please do not hesitate to ask in clinic for one.

As a direct result of your input, we have done the following:-

### General Practitioners

All General Practitioners of our CAH patients at GOSH will be sent out a letter, on our ideals in trying to improve overall care for all patients and how GP surgeries can help. Each will receive a protocol summary of care sheet, with guidelines on how to increase medication in illness, symptoms that should be reported to the team at GOSH, drug interactions to be aware of etc, as well as supplied a copy of the emergency letter. GPs will be asked to try to ensure that priority appointments are given. They will be provided other general guidelines including asking for their support with ensuring that patients have 'open access' to local hospitals. They will be asked to ensure the information supplied is accessible to locum, 'out of hours' doctors and practice nurses.

GOSH have found the GP's they work with to be very supportive and hope that the guidelines will be helpful. We are very grateful to the GP's who have helped with this project.

### Emergency Services

Professor Hindmarsh will be working closely with the Directorate of Emergency Services to implement a standardised Emergency Protocol which will be made available to all A & E Departments and Hospitals in the UK.



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### **In-house**

New redesigned identity emergency protocol cards for all those who are cortisol deficient have been issued. These clearly state our emergency contact numbers as well as emergency instructions for medical staff. These are available on line now on the Great Ormond Street Hospital Website <http://www.gosh.nhs.uk/medical-conditions/clinical-specialties/endocrinology-information-for-parents-and-visitors/conditions-we-treat/congenital-adrenal-hyperplasia/?locale=en> under Emergency Care, Cortisol Deficiency, cortisol replacement therapy card.

An official emergency letter giving specific emergency care instructions has been issued for parents to hand to the emergency services, casualty staff or 'out of hours' emergency clinics. This letter is available on the internet for easy access when abroad. This can be accessed through the GOSH and group website <http://www.cahisus.co.uk>

The letter gives detail of the doses of hydrocortisone to be used as we appreciate that in an emergency situation it is easy to forget. This will also assist ambulance personnel.

All parents as part of the patient's annual review will be offered individual training in giving the emergency injection, to ensure they are confident in administering it, please ask if you would like this before your next annual review.

During annual review appointments, each family will be issued a check-list to remind all to check expiry dates of hydrocortisone ampoules and ensure that the emergency kits are complete.

We have and are continuing to work in setting up individual protocols for our patients with their local ambulance services.

GOSH hope to set up open access/priority passes for all patients at their local hospitals and they will be provided with our emergency protocol.

The consultants at GOSH are working with parents to ensure they understand how to use these services. Please do not hesitate to ask about this if you do not have anything in place.

Reinforced to parents and patients the importance of wearing a Medic Alert at all times.

Taking the advice from the emergency services who suggest that due to the lack of knowledge regarding CAH it is recommended that the wording to be used on the disc should be 'cortisol deficient'

Specific protocols for schools and nurseries are available and the team at GOSH are happy if asked, to offer training in giving an injection to these establishments. These protocols are available in clinic and on line on both our group site and the GOSH website.

We have produced an 'Emergencies on Holiday' advice leaflet.

### **General Illness**

We are working on a 'What to do when your child is ill' leaflet. Although dealing with illness becomes easier through experience, we are very aware of how frightening this can be for new parents.

### **New Leaflets**

We have produced several new leaflets; on Hydrocortisone, Puberty and Bone Density which are all available on both our websites.

### **Questions and Suggestion Box**

We now have a Question and Suggestion Box which will be left out at clinic. Questions may be asked anonymously and please be reassured that the identity of anyone submitting a question will remain totally confidential. We hope this will give both patients and parents the opportunity to ask any questions that they might feel too shy or awkward to ask in clinic.

If the questions are marked totally private and an e-mail address supplied, these questions will be answered directly via e-mail.

Otherwise all other questions will be collated and answered in a private newsletter, sent to all our group members only.

We hope that these efforts will go some way to make things easier for our families and thank you all for your valuable input.

### **Fundraising**

Once again thanks to Graham Bennett and Jenny Owen for donating the proceeds collected when doing their charity run, to our Research Fund. The money will be very helpful as there are several projects we would like to take on but there is no funding available

### **Future Meeting**

Once again thank you all for all your support and for making our group so successful. We will let you know the date in April 2012 and venue of our next meeting before the end of the year.