



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

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

DEPARTMENT OF ENDOCRINOLOGY

GREAT ORMOND STREET CAH PARENT AND PATIENT SUPPORT GROUP NEWSLETTER CHRISTMAS 2011



Season's Greetings to All

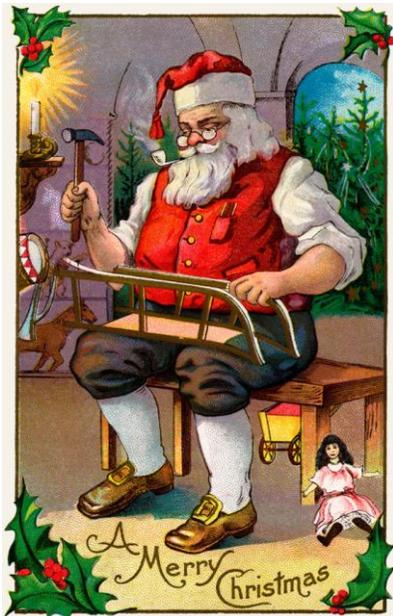
Our team at GOSH would like to wish you all a Merry Christmas and a very happy New Year!

Christmas Period

Please remember to ensure you have enough medication to cover the holiday season and that all emergency kits are in-date. Remember that we do have an endocrine registrar on call for any emergency advice that you may need on telephone number 020 7405 9200 and ask to be put through to the endocrine registrar on call.

New Website

We have redone our website (as a reminder here is the link <http://www.cahisus.co.uk/>) and I would like to thank Kathy, Chris and Darren for all their hard work. We have added our new leaflet titled 'Illness and Injuries' which gives guidelines in what to regarding medication dosages and we hope that you find it helpful.



Next Meeting

Our next meeting date will be 28th April 2012; we will let you know the venue once it has been confirmed.

Thank you all for the suggestions and questions, some which I have answered privately. The suggestions have been excellent and we hope to address as many of these as we can in our next meeting.

We do have some ideas on how to perhaps have a 'CAH Family Day', to give younger children the chance to meet and talk, but would like your input on this on 28th April.

We will go through 'Puberty and Management of CAH', which we now have a leaflet on, which is also on our website. It has been suggested we cover 'The Transition from Paediatric Care to Adult Care' and 'Impact of getting through school with CAH' - we will be happy to cover both these topics and will allow time for discussion.

We have been asked to discuss surgery - why, when, where, who and how? GOSH have an excellent team of surgeons and good psychological support. This is not really our area of expertise as paediatric endocrinologists and each child needs to be carefully assessed by the relevant specialities; however we are aware that this indeed would be most helpful to some. We feel that this would be more appropriately held as suggested, either as a break-out group discussion with the relevant experts or indeed at a meeting held by the specialists themselves and we will see what can be done to address this.

Our leaflets are now available in A4 format (where appropriate) on our website and in clinic format on the GOSH website, which has also been revamped. Please remember that you can always refer to the information on either website, at anytime from anywhere, including the emergency letter.

Wish very best wishes

Peter Hindmarsh

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

Department of Endocrinology – Adrenal Clinic