



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

GREAT ORMOND STREET CAH PARENT AND PATIENT SUPPORT GROUP NEWSLETTER JUNE 2012

Group Meeting 28th April 2012

I would like begin by thanking you all once again for braving the rain and especially to those who travelled quite some distance to attend our group meeting on the 28th April 2012.

We have had great feedback and thanks so much for this! It is certainly most gratifying that our meeting was again a great success and of course this would not have been possible without your participation. It was also a pleasure to welcome and meet several new families and we hope they will continue to join us.

Puberty

For those who were unable to make the meeting, here is a brief rundown of what we discussed. At the request of several parents, we talked about puberty which is a complex issue and we hope our puberty leaflet which is available on our website is helpful in explaining this to those who couldn't attend.

<http://www.cahisus.co.uk/leaflets.htm> CAH and Puberty

Circadian Dosing

The other topic we discussed was the Circadian Dosing method and again we have a comprehensive leaflet about this on our website.

There are many parents all over the world now practicing this dosing method which they have found very beneficial in helping to prevent certain side effects.

Circadian Dosing aims to replace the cortisol as close as possible to the way the body naturally produces it. This schedule usually entails giving four doses of hydrocortisone daily at specific times, rather than the usual three doses a day.

<http://www.cahisus.co.uk/leaflets.htm> Circadian Dosing

Using the Pump for CAH

There is also a new leaflet on our website, 'Using the Pump for CAH' which explains a little more about the Circadian Dosing and how using the pump method has been successful in achieving this and at present is the only method that can mimic the circadian rhythm.

<http://www.cahisus.co.uk/leaflets.htm> Using the Pump for CAH

We also have the 'Pump Video' on the website which is a series of clips to show how easy it is to use the pump.

A big thanks to Matt Hyde-Cooper, Chris and Sophie for all their hard work in doing this, in fact we have had great feedback and interest on this from people all over the world.

<http://www.cahisus.co.uk/CAH.htm>

Our Aim

What we would like to do is inform our patients of these different methods, so they understand the way they work and have the choice to use them if interested.

Parent and Patient Participation

We have decided to introduce a 'parent/patient time slot' at future meetings where parents, or even patients, are welcome to talk about their experiences in dealing with CAH. We hope that this will help not only to give some comfort to each other in that no one is alone with their worries but also a chance to share experiences and for everyone to get to know each other better.

We are looking for people to talk at our next meeting, as you know our meetings are informal and relaxed, so please drop us a line if you would be interested in doing this. The talk only needs to be brief.



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Great Ormond Street Hospital for Children 
NHS Foundation Trust
CAH Parent and Patient Group
Department of Endocrinology

Pump Story

Thanks very much to Angela for her brilliant, informative talk about using the pump at our last meeting and for allowing us to share a brief rendition of this in our newsletter.

Angela explained how they had come to GOSH for a second opinion as her daughter's health had been deteriorating for some years. Her daughter was suffering problems with prolonged viral illnesses, severe gastritis, headaches, and continual tiredness.

The centre Angela's daughter was under did not do 24 hour profiles but instead used blood spot samples, taken by finger pricks over a two day period, three or four times a year, in addition to occasional blood tests. This method does not show cortisol levels, it only gives a snapshot of the 17 OHP at that time the sample was taken.

Angela explained how she felt 24 hour profiles are extremely valuable and had, for the first time created clear picture of Alicia's cortisol uptake and potential issues relating to her health problems.

Since starting on the pump, her daughter's health has improved tremendously; she has only had one virus this winter, no longer feels unnaturally tired, has energy and feels much better in herself. She now rarely has a headache and has had no problems with gastritis.

She has found wearing the pump to be very easy having enjoyed skiing and a school trip abroad in the last few weeks, as well as a visit to her sister at university. She is now doing things she had not felt well enough or had the stamina to do before starting the pump.'

Questionnaire

Thank you all for filling in our questionnaire! Not only did this prove very interesting, it also highlighted many areas where we feel we can help our patients to achieve better control and the data collected is very helpful in guiding the research we are hoping to do.

Valuable Discussion Time

We had a lot of 'open' discussion time and again this was very helpful. We will most certainly try to implement the ideas put forward regarding the involvement of the psychology team at diagnosis.

This is what we hoped to achieve in having these meetings; to learn what our parents and patients want, how we can improve the care we give and how we can support everyone who deals with the condition in the best possible way.

Group Suggestions

We have taken on board all the other ideas and items mentioned including introducing families and we will work on these. We plan to set aside time to allow these discussion sessions at all meetings, as I think we all find them very valuable.

We ran out of time to speak about the transition to adult services but we hope to cover this at our next meeting.

Future Meetings

After a lot of careful consideration and due to the Olympics, sadly we will not be able to organise a family meeting during the summer and most unfortunately we have been unable to find a suitable venue which will allow us to accommodate children for our planned November meeting.

We have put this idea on hold until Spring 2013 perhaps around Easter time and we are already looking for a suitable venue, to hold an early Easter Egg hunt.

Our next meeting will be either mid-October or in November, we are still waiting for confirmation of the venue and we will advise you of the date as soon as we can. We appreciate that some need to book time off work, so please keep a look out on our Facebook page or on the website.

Once again thank you for your much appreciated support.

With best wishes

Professor Peter Hindmarsh