



CONGENITAL ADRENAL HYPERPLASIA SUPPORT GROUP

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Dr Sheena Parker
NSCAG
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Wellington House
133 – 135 Waterloo Road
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Re: Proposal for Hammersmith (Queen Charlotte's) Hospital to be the "National Centre" for Intersex Treatment

Dear Dr Parker,

On hearing from Miss Sarah Creighton (consultant gynaecologist & Obstetrician, EGA, UCL / Middlesex Hospitals) that a proposal to only have one "National Centre" for the treatment of all UK Intersex patients and this to be the Queen "the National Centre for Adolescent and Adult Females with Congenital Abnormalities of the Genital Tract" (Queen Charlotte's /Hammersmith) we are extremely concerned by this. We think this is an extremely misplaced idea. Many hospitals across the UK are providing far better service to Intersex patients and no single centre can cope with the entire Intersex population. A far better idea would be 8 – 10 centres with more training and expertise available the service could be so much better. The type of Health Care that would best fit intersex is "Specialised Commissioning" (regional basis, 8-12 centres) definitely not NSCAG (1 or 2 centres, handful of patients with very rare conditions).

The CAH Support group was formed in 1991 by RTMDC (now CLIMB) to provide peer support for families and young adults with CAH. The group has grown considerably and has been working to form close working links with medical teams at UCL / Middlesex, GOSH, Manchester Children's, Addenbrookes, Royal Hospital for Sick Children – Glasgow, Leeds Hospitals, Alderhey, Queens Medical Centre – Nottingham, Queen Elizabeth – Birmingham, Women's Hospital – Birmingham, North East Staffordshire Hospital, and The University Central Lancashire.

From these links we have developed an excellent working relationship with UCL / Middlesex Hospitals.

Also limited working relationships with the GOSH, Manchester Children's, Addenbrookes, Royal Hospital for Sick Children – Glasgow, Leeds Hospitals, Alderhey, Queens Medical Centre – Nottingham, Queen Elizabeth – Birmingham, Women's Hospital – Birmingham, North East Staffordshire Hospital, Leicester Royal Infirmary and The University Central Lancashire.

We approached the Queen Charlotte's / Hammersmith approx 4 years ago to try to form a working link with them but were told that they did not believe that support groups were beneficial and caused more harm. They informed us they were the "National Centre" for intersex and that no other centre should be treating patients. This has been kept very quiet and few people medical or otherwise actually know they exist as a centre for intersex treatment let alone be the "National Centre"!

We left it at that until in November 2000 when we were informed by the Queen Charlotte's / Hammersmith that they had a web site (<http://www.femgenab.org.uk>) for patient information to which they had, to our surprise put in links to our group and the AISSG. They also said they have their own in house support group, if you can call it that it meets twice a year in the Hospital and is just to discuss in a controlled environment how they are progressing with vaginal dilation. (no peer support!) We asked for details of their support group and any information for patients, again were refused though they wanted our information. We also asked if they had done or do any research into improving intersex treatment as we could find no published papers by their team, again no response.

Support group members that have been patients at the Queen Charlotte's / Hammersmith have reported that they were not happy with being kept in the dark about their condition being intersex. Secrecy about intersex conditions only compounds the problems of coping. People need to know so they can deal with and move forward in life. An open atmosphere within the medical centre is essential. The archaic "Ivory Tower" attitudes of the Queen Charlotte's / Hammersmith certainly should not warrant it being "National Centre".

From 6th August 1997 we have worked closely with the UCL / Middlesex after the support group was invited by Dr Gerard Conway (consultant endocrinologist) to join an open discussion with clinicians Miss Sarah Creighton, Miss Melanie Davies and Dr Lih-Mei Liao (clinical psychologist) and the AISSG (Androgen Insensitivity Support Group) to look at the way forward for intersex treatment. This was the start of a multi-disciplinary centre comprising endocrine, gynaecological / surgical, fertility and psychological treatment / support in a one stop clinic. Openness is second-to-none operating a purely transparent clinic with patients involved in all of their treatment.

On 26th February this year the first CAH patients open meeting was held for informal discussion on how the centre is progressing. The support group was invited to speak and join in.

Research is always on going at the UCL / Middlesex into improving CAH / Intersex treatment. The support group has been actively involved in helping. Support group members are often asking if more research is being done at UCL / Middlesex as they so enjoyed taking part and the openness of the researchers.

Dr Catherine Minto (clinical research fellow, UCL) and Miss Sarah Creighton have been doing invaluable studies into outcomes of vaginoplasty in adolescents and adults. The research is currently being written up. Updates are given regularly at support group meetings and conferences.

Dr Gerard Conway and Dr John Honor (biochemist UCL / Middlesex) have been researching a cheaper and more accurate method of carrier and diagnostic testing for CAH so that it can be made more readily available.

Professor Paul Stewart (consultant endocrinologist, Queen Elizabeth Hospital, Birmingham) has also worked with the support group on a small research project into the effects of living with CAH.

Dr Gerard Conway with Miss Sarah Creighton, Miss Melanie Davies (consultant gynaecologist & obstetrician), Dr Richard Stanhope (Paediatric endocrinologist) and the help of support groups wrote a very useful CAH adult information booklet, which the support groups have adopted as a main source of information.

Dr Richard Stanhope and Dr Peter Swift (paediatric endocrinologist, Leicester Royal Infirmary) helped with putting together the CAHG patients charter.

Dr Gerard Conway, Dr Richard Stanhope, Miss Sarah Creighton and Dr Catherine Minto have been guest speakers regularly at CAH / intersex conferences and meetings. All willingly give up their weekends to attend.

Many of our members come via Great Ormond Street Hospital and the UCL / Middlesex as well as Leeds and other major centres across UK. GOSH has an excellent working relationship with UCL / Middlesex and most paediatric cases of CAH are referred for surgery to GOSH from around UK if local centres do not have the expertise. GOSH patients are then transferred as adolescents / adults to the care of UCL / Middlesex for further surgery / treatment. GOSH specialists include Dr Richard Stanhope, Mr Peter Cuckow (consultant gynaecologist), Mr Christopher Woodhouse (consultant urologist) and Mr Phillip Ransley (consultant urologist), Dr Peter Hindmarsh (clinical endocrinologist), Dr Caroline Brain (clinical endocrinologist) and Ms Polly Carmichael (paediatric psychologist).

The support group has taken part in two medical documentaries discussing CAH C4 “Why Men Don’t Iron” and BBC “Body Chemistry” the UCL / Middlesex clinicians were most supportive liaising with the group and the programmes producers. To raise public awareness and acceptance of intersex issues is very important.

We often call on Leeds centre for advice with various questions we receive and are starting to develop a working relationship with them. Particularly Mr Adam Balen (consultant gynaecologist & Obstetrician) and Dr Julie Alderson (clinical psychologist).

The UCL / Middlesex has a world-renowned expertise for its multi-disciplinary open approach to intersex treatment is the envy of many UK and world centres.

How one centre Queen Charlotte’s / Hammersmith alone particularly with its archaic attitude towards patients can be a “National Centre”, is extremely alarming and will put intersex treatment back into the dark ages. Surely more than one centre of expertise would be more productive and cost effective. There are approx 30 paediatric centres in UK that deal with CAH and other intersex conditions. For adults there is much less expertise available approx 6 centres that really know how to treat intersex. Of those the UCL / Middlesex, Leeds and Addenbrookes being most knowledgeable.

The strong working relationships we have formed with the regional centres like UCL / Middlesex are now at considerable risk especially if a centre that doesn’t believe in patient involvement in their own treatment is to be “National Centre”, not once has Queen Charlotte’s / Hammersmith let their patients know that there are intersex support groups. Patients from there find out via GP’s and the internet plus many other support directories that we are listed in.

The so-called “New – NHS” is supposed to be focused on the patient and with society’s more open attitude this should be a good thing. We hope bureaucracy will not enforce such a damaging plan.

Considering that there are approximately 2500 babies born each year in the UK with intersex conditions, how can one centre cope with this increasing number of adults? Logistically it would also be very difficult for all patients to go to a single centre for treatment regional centres are far better suited particularly if they all link together to share information, resources, expertise and training.

Intersex may be a minority of the population but its increasing and its one that does have a voice. We no longer accept that we are to be trodden on, hidden away and our feelings brushed aside.

We also have strong links with groups like AISSG, AHN, Child Growth Foundation, Genetic Interest Group who also have strong relationships with the regional centres UCL / Middlesex and Leeds.

We will certainly be taking further action if we are not happy with the outcome and will bring the attention to the media whom would be in their element with the abounding medical scandals and legal claims especially with the forthcoming general election.

It will be a day of grieving within the intersex community if the proposed plan is enforced.

We urge you to consider all the implications of continuing with this very outdated plan as the world and treatment have moved on considerably. The “Ivory Tower” has long since been demolished in so many centres and should never return as treatment will return to the “dark ages” of secrecy and shame to be intersexed.

Yours Sincerely

Melissa L. Cull
CAH Adult Support Co-ordinator