



Miss Melissa L. Cull  
17 Newton Road  
Lichfield  
Staffordshire  
WS13 7EF

Tel: +44 01543 252961

E-mail: [ahn@mlcull.demon.co.uk](mailto:ahn@mlcull.demon.co.uk)  
[www.ahn.org.uk](http://www.ahn.org.uk) (under construction)

15 May, 2001

Dr Sheena Parker  
NSCAG  
Room LG04  
Wellington House  
133 – 135 Waterloo Road  
London  
SE1 8UG

**Re: Proposal for Hammersmith (Queen Charlotte's) Hospital to be the "National Centre" for Intersex Treatment**

Dear Dr Parker,

It has come to our attention that it is proposed to enforce the "National Centre" Queen Charlotte's / Hammersmith (QCCH) as the only treatment centre for intersex conditions including CAH. We are most alarmed and shocked to hear this. The UCL / Middlesex and Leeds centres plus other regional centres provide far better services to intersex patients. At this point we wish to confirm that the UCL / Middlesex and Leeds medical staff have nothing to do with the information we have obtained on the QCCH. We strongly recommend this totally bureaucratic misplaced proposal does not go ahead.

The AHN support group was formed in January 1999 to provide peer support specifically for adults and teenagers with CAH via e-mail and informal meetings. Also helping with research into the improvement of treatment for CAH and other intersex conditions. We also have a web under construction.

Our first meeting 19<sup>th</sup> September 1999 was held in Lichfield with guest speakers from UCL / Middlesex. Dr Gerard Conway (consultant endocrinologist, UCL / Middlesex), Dr Richard Stanhope (paediatric endocrinologist, GOSH), Dr Catherine Minto (gynaecology clinical research fellow, UCL), Mrs Kathryn May, (psychosexual psychologist, Lancashire) and Mr Kevin Hobbs (psychosexual therapist, Lancashire).

From the groups inception we have formed a strong working relationship with the UCL / Middlesex. We have also formed a strong working relationship with the University of Central Lancashire in regards to the

psychological issues of CAH. Within the Leeds Hospitals too we have developed a working link. We are constantly working to form links with centres around the UK and overseas.

Strong links with CAHG, AISSG, CaF, CGF and GIG have been formed along with overseas groups in Sweden, Australia, New Zealand and USA. We also link with ISNA and UKIA. CAHG link is strong because I am also CAHG Adult Support Co-ordinator.

AHN is actively involved in helping with research projects with UCL / Middlesex in "Surgery Outcomes" in CAH with Dr Catherine Minto and Miss Sarah Creighton (consultant obstetrician & gynaecologist, UCL / Middlesex). All our members that took part found it extremely worthwhile and very refreshing to meet such friendly researchers.

The University of Central Lancashire, Mrs Kathryn May and Mr Kevin Hobbs performed a research survey into the need for a psychosexual counselling service for adults with CAH. The results of which were presented at the first AHN meeting.

AHN also helped Dr Gerard Conway who wrote the CAH adult info booklet gather information for it along with Dr Richard Stanhope, Miss Melanie Davies (consultant Obstetrician & gynaecologist) and Miss Sarah Creighton, CAHG and CGF.

When AHN was formed we approached the QCCH to say we had formed a group for adults and teenagers but we got a very disappointing response in that they say support groups cause more harm and they don't encourage people to join. At that we gave up on them because from links with other support groups and former patients of QCCH there reputation precedes them for not being patient friendly but on the contrary paternalistic and arrogant. Patients have to live with their conditions 24 hours a day, 7 days a week, 365 days a year for life and to go into clinics that have staff that think they are way above anyone and you are nothing is extremely upsetting. To a patient this "we know best you know nothing" attitude is soul destroying.

I am currently writing and compiling a book for AHN on "CAH surgery & Dilation" aimed at providing the patient, parent, GP and Nurse accurate information on all aspects of genital surgery, non-surgery and treatment. This is very long overdue as information is very patchy and inaccurate at present. For this all the regional centres were contacted in order for them to have the opportunity to contribute an article. We had a 50% response rate and all positive. The main inspiration and encouragement though has come from the UCL / Middlesex, GOSH and the Leeds centres. Surprisingly the QCCH replied and an article was sent in from them. Though we must say it is more of an advert for the centre rather than an article giving useful information.

There are many centres in UK providing fabulous care and treatment to their intersex patients. Treatment and care at UCL / Middlesex "Combined Endocrinology, Gynaecology and Psychology Clinic" is 2<sup>nd</sup> to none, it is world renowned for it's patient friendly caring experts. The Leeds also is modelling itself on their ideas and is also very well respected. Multi-disciplinary care is the way forward, a must not an option. Clinicians working with and involving their patients in decision-making is so much better for all – the patient understands their condition better and so does the clinician. In this day and age where informed consent is a requirement of everything it is certainly essential that a patient knows all the pro's and con's of treatment.

If the proposal goes ahead we will not hesitate to take further action. With the Election looming nearer and media itching for scandal with all the legal action against the health service at present at an all time high, we will certainly not hesitate to voice our views as service users to a wider audience. We do not want our conditions brushed under the carpet, we want to be accepted by society not and hidden away and treated badly as we have been in the past and are still in some centres.

Big is not always beautiful and in this “Nanny State” we do not want telling how we should be treated we as patients want an input to our treatment so a single centre would be a disaster. Smaller specialised regional centres that all work together under Specialised commissioning (8 –12 centres) would be much better suited as they would give better access and more opportunity for medical person’s to train in specialising in intersex treatment.

We urge you to listen to us the service users and other medical professionals before you make what could be the most monumentally catastrophic decisions in intersex treatment.

Kind regards.

Yours Sincerely

Melissa L. Cull  
AHN Founder