



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

Tel: +44 01543 252 961
Fax: +44 01543 411 761
Mobile: 07976 378 293 (Daytime Weekday)

E-mail: ahn@mlcull.demon.co.uk
www.ahn.org.uk (under construction)

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The Right Honourable Mr Blair
Prime Minister
10 Downing Street
London
SW1A 2AA

Re: Proposal for Hammersmith (Queen Charlotte's) Hospital to be the "The National Centre for Adolescent and Adult Females with Congenital Abnormalities of the Genital Tract"

Dear Mr Blair,

We would like to bring to your attention what we consider to be an extremely misplaced proposal / enforcement by the "National Specialised Commissioning Advisory Group" (NSCAG) of the Department of Health regarding the proposal to enforce a single "National Centre" the Queen Charlotte's / Hammersmith Hospital to be the "National Centre for Adolescent and Adult Females with Congenital Abnormalities of the Genital Tract".

The very title of the supposed "National Centre" at QCCH in a way echoes their denial of the existence of intersex conditions, by NOT mentioning the word "intersex". This was done without any consultation with support groups, patients and other major intersex treatment centres. According to the NSCAG web site it is supposed to consult with patients, support groups and other specialists in the fields it is considering centralising. We request your help in preventing this and having instead 8 - 12 Specialised Regional Centres throughout the UK and Northern Ireland.

NSCAG was set up by a previous Conservative government for centralising treatment of very, very rare conditions, 400-1000 patients. Intersex conditions affect approximately 2500 births per year and intersex affecting approximately 1 in 50 families, which is way out of the jurisdiction of

NSCAG. Health authorities from all parts of England, Scotland, Wales and Northern Ireland are being requested to transfer patients to the National Centre. Furthermore some intersex conditions i.e. Congenital Adrenal Hyperplasia (CAH) are life threatening and to centralise treatment be it surgical or otherwise could only be a death sentence to intersex people in an emergency or acute situation people couldn't get treatment locally, regionally as other centres wouldn't know what to do. Not only is NSCAG trying to centralise intersex treatment to a single centre but also other common conditions such as Diabetes, Parkinson's disease, Cardiology and the Genetics service to name but a few.

Being intersexed is not a threat to society, we are just people wanting to live our lives within the law and have feelings like everyone else and would like to be treated as such, not as "freaks" to be fixed. We are not, as many Psychiatrists put it, 'mentally unbalanced' to be hidden away, institutionalised and experimented on. Society should not make us feel ashamed to be alive just because we have ambiguous genitalia. Nor are we anything to do with 'Transsexualism' (that is an entirely different medical condition that affects the sexually dimorphic nucleus of the brain), which we are often confused with. Intersex is not something that needs to be fixed it is just a variation of genetic make-up. Most intersexed people are highly educated and have excellent careers.

Where will the right to a second opinion (as stated in the government's NHS patients charter page 3 "Access to Services". Part 4 - you have the right to, be referred to a consultant acceptable to you, when your GP thinks it is necessary, and to be referred for a second opinion if you and your GP agree this is desirable) go if we are all forced to go to a single centre? There will be nowhere to go for a second opinion!

The Patients charter also states page 4 last paragraph patients have a right to "have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before you decide to agree to it". Patients with intersex conditions rarely get full explanations of what is going to be done to them so they do not know all the risks involved. The same goes for parents with intersexed children very often they are told by hospitals that this is what has to be done and no further explanation. So informed consent is rarely so with intersex. Who has the right to adjust people's genitals to conform socially, whose body is it anyway? In truth only the person themselves should make that decision, but does that happen in this country - the answer in 95% of intersexed persons is no, hospitals and parents make that irreversible decision as a child. Intersex in itself is not a life threatening condition, CAH is life threatening as it causes a block on Cortisol and often salt retaining hormones which are required for life.

And Patients Charter page 5 paragraph 1 "have access to your health records, and to know that everyone working for the NHS is under legal duty to keep your records confidential". Having an Intersex condition has long made it extremely difficult and nigh on impossible to obtain medical records, many are stamped do not tell patient or parents (if child) under any circumstances the diagnosis. Many intersexed people only find their diagnosis when applying for a mortgage or health insurance and have a medical for work requiring genetic testing - nobody should be subjected to such humiliation and shock of finding out in from an insurance sales person, bank or building society.

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 children and adults? Logistically it would also be very difficult for all patients to go to a single centre for treatment specialised regional centres are far better suited particularly if they all link together to share information, resources, expertise and training.

As a government known for protecting racial, cultural and social minorities we as intersex people request that you help us to maintain our medical treatment regionally in specialised multidisciplinary centres including the world renowned UCL / Middlesex Hospitals and also the Leeds Royal Infirmary whom both provide excellent care for intersexed people. You promote the "New NHS" that is supposedly patient centred let us keep regional care and have 'Specialised Regional Treatment Centres' that liase with the patients for their needs.

Both the government and the NHS needs to remember the intersex patient is a person with feelings, not an object, nor a disease or an illness, we are real people - perhaps take a leaf out of the Bombay Hospital, India motto:

"A patient is the most important person in our hospital.
He is not an interruption to our work,
He is the purpose of it.
He is not an outsider in our hospital, he is part of it.
We are not doing him a favour by serving him,
he is doing us a favour by giving us the opportunity to do so."

*Motto of the 'Bombay Hospital',
adapted from a saying by Mahatma Ghandi*

We have attached copies of the responses from various groups to NSCAG on the issue of centralising treatment for Intersex to a single centre. NSCAG have so far refused to meet any patient support group representatives, nor replied to some letters. The majority of clinicians and hospitals support specialised regionalisation of intersex treatment centres ...so why this proposal... has even got through to enforcement stage with little or no consultation is beyond our comprehension.

As service users we are very concerned that patients were not consulted on such an important life-impacting decision regarding service provision.

We would like to point out that we are not a political group we are just a patient support group that gives support to people and families with CAH and helps those medics interested in improving intersex treatment with research.

We would like to request a meeting to discuss the issue further.

The other groups may contact you separately.

We hope that you will consider this serious matter very carefully.

Kind regards,

Yours Sincerely,

Melissa L. Cull
AHN Founder (Also CAHG Adult Support Co-ordinator, CLIMB Befriender)

Enc. Copy of letter to NSCAG, Copy of other responses to NSCAG, CAH Adult info booklet,
Support Group Info Sheet
CC. Minister for Health