

AIS Support Group

PO Box 269

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May 8<sup>h</sup> 2001

Dr Sheena Parker

NSCAG

Room LG04, Wellington House,

133-155 Waterloo Road,

London SE1 8UG

Dear Dr Parker,

**Re: Proposed "National Centre for Adolescent and Adult Females with Congenital Abnormalities of the Genital Tract"**

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We were alarmed to learn in the last few days that Hammersmith Hospital (previously Queen Charlotte's) has been nominated the National Centre since 1996 and that soon this status will be enforced by your organisation, and no other units will be able to undertake this work due to funding and referrals being blocked.

Since 1996 the conferring of National Status has neither been generally broadcast nor enforced. During this time Regional centres offering multi-disciplinary services to patients have grown "organically" as a result of a more enlightened attitude of certain professionals who have moved away from the paternalism and secrecy of the past to pro-active management of cases in partnership with the patients.

Many members of the Androgen Insensitivity Syndrome Support Group are intelligent and successful women who have only recently been able to piece together the fragmented picture of their lives, caused by the past secrecy and taboo.

In today's allegedly patient-focused NHS, a strong relationship of trust and co-operation has been built up over the last 5 years between patients and professionals in these Regional centres, culminating in a Symposium planned for January 2002 at which both parties will debate on an equal-status basis the best way forward for the future.

All the hard work, the financial investment and most importantly the bond that has developed over this period are at risk due to what appears to be a bureaucratic requirement.

"Centralising" all services will cause considerable upheaval to patients who will have to start again building a relationship with their consultant, and a logistical challenge for the Centre, which claims to have the capacity for the workload. We doubt this claim and can almost certainly predict the resulting tabloid headlines.

At this politically sensitive time (General Election looming) and the current airing being given to clinical litigation claims, the tabloid press would leap at an opportunity to stir up interest in a good old-fashioned freak show - there is great public confusion surrounding Intersex conditions and Transsexuals.

Therefore, we urge you to consider what is best for the patients and step back from enforcing this outmoded dogma - the world has moved on since 1996, and the genie is out of the bottle never to return.

Attached is a more detailed letter from our Publications Editor which sets out the extent of the co-operation between the AIS Support Group and in particular the teams from the Middlesex/UCL and Leeds hospitals. We trust this will highlight the advisability of not taking a retrograde step.

Yours sincerely,

Mrs S. Woodgate

Committee Member