

AIS Support Group (UK)

www.aissg.org

Media Guidelines

(11 September 2009)

In principle, we are interested in raising awareness of AIS and related intersex conditions through public education. There has been growing UK media interest in this area since these conditions came out into the open (largely as a result of the group's activities) in around 1995. We have had some dealings with newspapers, magazines and TV film companies in recent years, with mixed results. It has led to some helpful coverage which has normalized the conditions by removing some of the stigma that has surrounded them. However, our co-operation has also been abused; by inaccurate medical details, sensationalized stories, and inappropriate or offensive headlines or voice-overs added without consultation etc.

The UK group is run on a day-to-day basis by just two volunteers who also have busy full-time occupations. A large percentage of their spare time is taken up in answering enquiries from people in distress, researching/writing our newsletter and web site, liaising with doctors etc. They do not have time to interface with the media unless it is clear, from quite early on, that group members stand to gain significantly from such co-operation.

All our members' details are confidential and we will only ask members if they wish to contact you if we feel that the project has been well-researched and is likely to advance our cause in a sympathetic way. We have several hundred people on our list and we do not have time to contact them every time a media professional makes a casual enquiry. Very few affected people will be willing to talk to the media. Some of these have already done so on previous occasions and become burnt-out. Others will be reluctant to volunteer for interviews, unless they can be advised of your credentials and objectives.

Intersex is a complex and confusing area. We recommend that you do a lot of background reading before you even think of talking to affected people. Please study our web pages carefully before going any further. The "AIS in Articles/Books" and "Raising Awareness" pages provide details of past media projects. In order to get a feel for what intersexed women are discussing between themselves, please obtain copies of our newsletter, ALIAS (available on CD-ROM, please email us for details) and don't forget the "Personal Stories" page on the site.

Please be aware of some common areas of confusion, as follows:

1) The difference between 'intersex' and 'ambiguous genitalia':

Consider the 3-part alignment or axis comprising a) the *sex chromosomes* (usually XX or XY), b) the *gonads* (usually ovaries or testes) and c) the *external genitalia* (usually male or

female). Intersex can be thought of as a ‘crossing over’ or mixing of one or more of these male/female components in a particular person.

The word ‘genitalia’ refers to what’s on the outside of the body. Some intersexed people have so-called *ambiguous genitalia* (or maybe, in some cases, a clitoris that is somewhat larger than average). But many do not. Women with the complete form of AIS (CAIS), for example, have XY sex chromosomes and internal (abdominal) testes but they have totally female external genitalia (i.e. not ambiguous). Yet they are still intersexed. Even some doctors use the term ‘intersexed’ when they really mean “an intersexed patient *who has ambiguous genitalia*”.

2) Misuse of the term ‘hermaphrodite’:

A hermaphrodite, in the mind of the general public, is a creature that is in fact purely mythical, one that supposedly has a *complete working set* of both male *and* female internal and external organs (such that the individual can, in theory, impregnate itself). This is not humanly possible.

Occasionally a person may have sex chromosomes that are mixed XX/XY (mosaicism) and the gonads may be mixed ovarian/testicular (e.g. an ovotestis); and in these cases the genitalia will probably be ambiguous. Medicine took over the literary term ‘hermaphrodite’ in the 1800s and employed it (later qualifying it to become ‘true hermaphrodite’) to describe this situation. This is extremely rare (probably only one or two members of our group are in this situation), much rarer than the intersex conditions such as AIS etc.

Jeffrey Eugenides was incorrect in his novel, *Middlesex*, in referring to Callie (who had 5-alpha-reductase deficiency) as a ‘hermaphrodite’ – something that the press, of course, picked up and propagated. Callie, like the vast majority of our members with conditions like AIS, 5-alpha-reductase deficiency, Swyers syndrome, etc., is what some doctors charmingly refer to as a ‘*male pseudo-hermaphrodite*’. This is an umbrella term for someone with the type of misalignment referred to earlier, e.g. with certain discrete male characteristics (XY sex chromosomes, internal testes) yet certain discrete female characteristics (female external genitalia and general body form, breasts etc.). There is also a set of conditions (congenital adrenal hyperplasia or CAH, for example) that come under the umbrella term ‘*female pseudo-hermaphrodite*’ (XX sex chromosomes and ovaries, with masculinization of the external genitalia).

Most of our members detest these ‘hermaphrodite’ terms, just as those with AIS find the old name for their specific condition (testicular feminisation syndrome) deeply offensive. For our members, many of whom were not told the truth by doctors/parents, it is often these terms that they discovered in medical libraries/bookshops when searching for the information that will allow them to make sense of their obviously unusual bodies/physiology. This is very traumatising for a teenager who may, in all respects except for her internal organs, appear to

be female (and who has often only come to medical attention through a failure to menstruate) and many of us feel these terms should be banned from the literature.

For more details of the above issues see www.aissg.org/21_overview.htm#terminology.

We hope you understand our hesitant and cautious tone. Such projects can only be successful and mutually beneficial if we feel that you are truly trying to understand the condition, and that you would attempt to further our cause (as opposed to us merely helping you to sell more magazines, TV films etc.). If you are still keen to involve us in a project, please answer the following questions so that we can consider your request more fully:

1) Please provide several paragraphs outlining:

- a) the title, style and content of your proposed programme/article
- b) what angle you are taking
- c) whether it is part of a series
- d) where/when it is likely to appear.

2) Please tell us about the practicalities:

- a) how long is it?
- b) roughly how much of it will be devoted to AIS?
- c) how many people are you hoping to interview and in what way/where?
- d) are you willing to disguise their identity if necessary?
- e) do you want UK or US interviewees?
- f) how much freedom will you give AISSG/interviewees on the content and how it is presented?
- g) are you planning to sell the article/film abroad?

3) Please give us some assurances that:

- a) interviewees will be able to see/hear the item before it is filed
- b) you agree to include our **web** address (**not** the email address) in your article/programme or on an associated web site (this is an absolute condition of us agreeing to collaborate)
- c) you will make a donation to the group's funds (and provide details of appearance fees/expenses for participants).

4) Do you have a medical adviser on this programme/article?

- a) if so, who?
- b) are you hoping to interview other doctors, and if so, who?

5) Please tell us about yourself:

- a) are you a journalist, researcher etc?
- b) if you are freelance, which outlets have you written/worked for before?

Thank you, AISSG (UK)