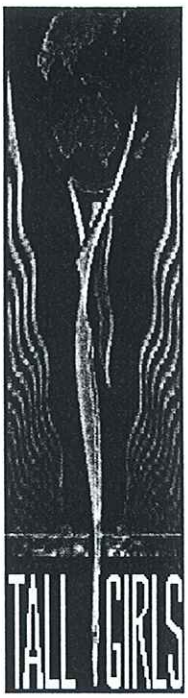

TALL GIRLS Inc. NEWSLETTER

Tall Girls Inc.
P O Box
CARNEGIE VIC 3163

Janet Cregan-Wood	**Chairperson**	**Phone & Fax**	**03 9818 5421**
Trish Gardner	**Vice Chairperson**	**Phone**	**03 97310078**
Astrid Hiron	**Western Australia**	**Phone & Fax**	**08 9534 8454**
Catherine Cuthbert	**Queensland**	**Phone**	**07 3846 2028**
Wendy Morphett-	**South Australia**	**Phone**	**08 86881961**

A support group to promote the interest of Diethystilboestrol (DES) and Ethinylestradiol (EE) exposed Tall Girls

CHAIRPERSON'S REPORT

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It took only a little over three years. A quite remarkable journey from an initial meeting of five Tall girls, and three mothers, two weeks after reading a newspaper story, to achieving a world first study, funded by the National Health and Medical Research Council (NHMRC)

As I have said before, this has not happened without the participation of all those women (approximately 230), who have responded to the various media stories and shared their testimony with us. It was from the concerns raised by this testimony that we developed our Final Statement of Interest which clearly defined our role as the primary stakeholders. We would not let go or give away ownership of our experiences. We also stated clearly, the need for independence in any research to be undertaken. I think that we can be assured that this is the case.

So, now we embark upon the next stage, the research is underway.

One of the really important factors here, is participation. Participation of those who were assessed and treated with estrogens; those who were assessed but not treated; parents of those who were treated. Equally important is the participation of treating doctors, to provide their records, to provide information of their treatment regimes. And we are really reliant on goodwill here...if we are to have the participation of all parties, then we ultimately will have a more meaningful outcome, one that will be of great benefit, one that is world class.

Tall Girls Inc. role as the primary stakeholders has been acknowledged and we have been recognized by being given two positions on the Reference Group for the study. Our primary role will be to bring our experience and insights but will have no influence on the outcomes. We do not want this, nor should we...our declaration for independence is just that....independence from influence from us, the advocates and independence from influence from those who treated us or have had vested interests in the treatment.

Tall Girls Inc. has provided their contact list to the research team. This list only details the name address and telephone number of all those who have contacted us. From the very beginning, through the newsletters and phone conversations, we have always stated that our most important objective was to find out what the long-term effects of our treatment were. All other information has been kept confidential, as promised. Medical records that will be made available to the research

Zie pagina 7: summary Leander

Summary

In our May 2000 newsletter, we reported that a student researcher in The Netherlands was going to undertake an investigation of growth suppression treatment there. Here is the summary from her research paper. We thank Leander for sharing it with us.

In Australia, tall girls had been treated with DES from 1959 until the mid 70's to stunt their growth. Some of these women have, together with women who have been treated with ethinylestradiol for the same indication, established an organisation (Tall Girls Inc.) whose goal is to study the research for the treatment and its effects. In pursuance of this information the Dutch DES Centre has called in the Science Shop for Medicine to investigate if DES has been used in the Netherlands in the growth stunt treatment.

The main question in this research is therefore 'Has DES been used in the growth stunt treatment in the Netherlands?' Research on literature and practical research has been executed to obtain an answer to this question. The literature search consisted of all relevant published articles (national and international). The practical research consisted of interviews with paediatricians (paediatric endocrinologists). The research was extended to trace the global image of the treatment, paediatrician's opinions, opinions of patients and parents, the possible long-term effects of the treatment and the set up of new research.

From 1968 Dutch tall girls were treated with high dose estrogens (ethinylestradiol). In the beginning they used Premarin in a dose of 200 or 300 μg in combination with Provera (medroxyprogesteroneacetate, 5 or 10 mg a day) during the first 12-14 days of the calendar. Later on Lynoral was used in a dose that was reduced to 100 or 200 μg in connection with the side effects.

The main conclusion of this research was that DES has never been used for this indication in the Netherlands. Comparing the pros and cons the choice was made to use ethinylestradiol (EE) for the growth stunt treatment because of the fact DES had no advantages compared to EE. Above that DES had the disadvantage of pigmentation of the areola and mammae often occurred after usage.

Nothing can be said about the number of women who are treated yearly for their tall stature in consequence of the fact estrogens are not registered for this indication.

It could also be concluded from the research that more attention should be paid to the possible usage of somatostatin-analogues in the treatment of tall stature. More attention should be paid to the role of psychosocial factors and the mother's role that contribute to the decision to treat or not to treat. A new research into the long-term effects of estrogen treatment should be conducted. The Australian research-model can be used as a guideline. Finally the possible role of estrogens in the development of endometriosis and mamma carcinoma should be investigated.

Leander Wemmenhove
Science Shop for Medicines
University of Groningen
The Netherlands

(The Science Shop for medicines is a community based Research Institute of the School of Pharmacy. It aims to empower patient organizations and other community based groups by performing research and disseminating objective knowledge on medicines.)