

Turner Syndrome Support Society

13 Simpson Court ● 11 South Ave ● Clydebank Business Park ●

Clydebank G81 2NR
Tel: 0141-952-8006 ● Fax: 0141- 952-8025
www.tss.org.uk ● Turner.Syndrome@tss.org.uk
Registered Charity No 1080507

Dear Dr Longson

5th January 2010

Health Technology Appraisal

Human growth hormone for the treatment growth failure in children (review)

Appraisal Consultation Document

Thank you for sending a copy of the above document to the TSSS and for the invitation to comment on it. You specify four headings initially on which we should comment. We will restrict our comments in the main to Turner Syndrome.

i) Do you consider that all of the relevant evidence has been taken into account? The analysis is very extensive and we are sure that as far as is possible you have used all available published evidence.

ii) Do you consider that the summaries of clinical and cost effectiveness are reasonable interpretations of the evidence and that the preliminary views on the resource impact and implications for the NHS are appropriate? The summary of clinical effectiveness was as expected and clearly in Turner Syndrome the use of GH is effective. The summary of cost effectiveness was also very acceptable to us but there were wildly varying costs in relation to centimeter of final height gained or in relation to QALY. See paragraphs 4.2.1, 4.2.2, 4.2.9, 4.2.10, 4.2.17, 4.2.18. These variations were seen in absolute cost or relative cost (when compared to growth hormone deficiency). As an example of the variation relative cost per centimeter were from x 2 to x 4.5 approximately. Different data sets and methodologies generate these variations. We think a reasonable summary would be that it costs about twice as much per extra centimeter of final or adult height when treating a girl with Turner Syndrome compared to a child with growth hormone deficiency, not a surprising ratio considering the comparison of an individual who is GH replete to one who is deficient. We very much agree with the Committee who state in paragraph 4.3.8 that the utility estimates, “may not capture the potential increased utility from normal height gain during childhood”.

iii) Do you consider that the provisional recommendations of the Appraisal Committee are sound and constitute a suitable basis for the preparation of guidance to the NHS? Yes

iv) Are there any equality related issues that may need special consideration? No.

You asked for comment on the proposed date for review of guidance, namely May 2013. In our opinion this is rather early. The committee has made some suggestions for more research and it is highly unlikely that such research in the field of growth could be completed within that time frame. We would suggest 2018 at the earliest. In conclusion, we would like to express our gratitude to the Committee for the very thorough analysis that it has conducted and for continuing to support the use of GH for girls with Turner Syndrome. We are also grateful that our observations have been acknowledged and understood by the Committee.

Yours sincerely

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