

briefing

ECONOMIC EVALUATION OF GROWTH HORMONE THERAPY

Introduction

Treatment of children with growth hormone is well recognised under the NHS and its cost (between £5,000-£10,000 per annum per child) has generally been accepted. Since the biotechnologically produced hormone (rhGH) first appeared on the market in 1985 it has been increasingly prescribed by general practitioners at the request of hospital consultants whose pharmacies felt unable to pay the high cost.

With the introduction of 'indicative prescribing amounts' for general practitioners, however, many families with children receiving rhGH fear that their family doctors may now begin to refuse to prescribe the hormone. Despite the Secretary of State's assurances that the indicative prescribing system 'will not interfere with the GP's clinical freedom to prescribe the medicines that he or she considers necessary for a patient's treatment',¹ the families believe that FHSAs may feel that they should exert 'downward pressure' on GP prescribing. The use of growth hormone, which many GPs may regard as a cosmetic therapy rather than a medical necessity, may be at risk.

In order independently to assess its value it was decided to use the health economist's technique called 'willingness-to-pay' to evaluate the importance which families placed on their children receiving rhGH. Since it was desirable not to create anxiety that treatment might cease to be available under the NHS, parents were asked how they would behave if they lived in another country where medicines were not available free of charge.

The concept of measuring recipients' theoretical willingness to pay for treatment which is in fact free is well established and has been validated in a number of situations.² As Galler has stated 'it seems to be the only feasible way to get measurement of the intangible effects of health care programmes presently available.'³

Method

A readily available sample of families whose children were receiving, or were due to receive, rhGH existed within the membership of the Child Growth Foundation. There are approximately 600 families who are members of the Foundation, of whom 450 were parents of affected children. It is recognised that this sample may be biased towards more committed parents than the population of

parents as a whole, but there was no easy way of preparing a more representative sample.

It was decided to pilot the questionnaire to be used in the survey with two groups of parents in the London area, on two evenings in January 1991, at meetings attended by 17 and 13 families respectively. At each of the meetings the parents were asked to assume that the questionnaire and its covering letter had been received through the post, and the discussion of the questionnaire was only conducted after the completed forms had been collected.

The initial questionnaire contained three questions. One asked what proportion of weekly income parents would be prepared to spend on growth hormone for their child. The second asked the average weekly income for the family after tax. The third asked what *amount* they would be prepared to pay each week. The word 'prepared' was used as a compromise between the two alternatives 'able to pay' and 'willing to pay'. It is probable that these two alternatives would, for obvious reasons, produce quite different results, although no definitive studies have been conducted on this point.

At the first pilot meeting it was agreed that the phrase 'willingness to pay' should be removed from the title of the questionnaire, as there was no suggestion that parents would be 'willing' to pay under the National Health Service. More substantively, it was pointed out that many parents who would be unable to pay out of current income might be prepared to take special steps such as re-mortgaging their house, selling their car, or taking a second job if that were necessary to pay for their child's treatment.

Thus for the second pilot meeting the questionnaire was modified, and an additional question about whether the parents would be prepared to take such 'special steps' was added. No substantive further modifications were found necessary at the second pilot meeting, and the final questionnaire and covering notes are set out in the Appendix. This was posted in February 1991 to members of the Child Growth Foundation, who were asked to return the questionnaire within a fortnight in a reply paid envelope. As no indication of the name or address of the respondents was asked for (in order to give them an absolute assurance of confidentiality) it was impossible to follow up non-respondents.

Results

From the 450 parents circulated with the questionnaire, 182 forms were returned for analysis. These included the questionnaires obtained at the pilot meetings, as these parents were specifically instructed not to complete another form. This is a 40.4 per cent response. The analysis of the results is shown in the Table.

Figure 1 shows the percentages of weekly income which parents would be prepared to pay, for three representative income brackets: those with weekly incomes between £101 and £150; those with incomes between £201 and £300; and those with incomes over £500 per week. There is an obvious gradation of results, with lower income parents prepared to devote smaller percentages for their child's treatment. In the highest income group almost 40 per cent of parents would be prepared to allocate over 30 per cent of their income in order to ensure that their child received the treatment.

Figure 2 shows a similar pattern for the same three income groups in terms of the *amount* parents would be prepared to spend. No low income parent would be prepared to spend more than £30 per week, with the great majority being prepared to spend between £1 and £10. Twenty per cent of these parents would be prepared to spend nothing, confirming the percentage figures given in the previous Table. For the highest income group, about 25 per cent said they would be prepared to pay more than £75 per week.

Figure 3 shows a reconciliation between the answers shown in the first two tables. Because the bands for responses were fairly wide, it is predictable that the great majority of the 'percentage' answers for individuals were compatible with their answers for 'amounts'. For each of the income groups apart from the highest, 90 per cent of respondents gave compatible answers. Low income groups tended to give lower answers for their percentage than for their amounts. For the other income groups (as had been expected) individual answers tended to indicate that respondents were prepared to give less when they thought in terms of amounts rather than when they thought in terms of proportions. This discrepancy was most marked for the highest income group, where over 20 per cent indicated that they would be prepared to pay a smaller amount than would have resulted from their percentage figure when applied to their stated income.

Figure 4 shows the responses to the question about being prepared to take 'special steps' (such as a second mortgage) to finance treatment with growth hormone. Overall, 126 out of 163 parents who answered this question said they were prepared to take special steps. That is 77.3 per cent. The answers are shown broken down in the figure according to the proportion of income parents would have been willing to pay. Apart from a low positive response from those who would contribute none of their income, it is clear that a great majority in all groups of parents would be willing to take special steps in addition to contributing out of weekly income. Indeed every one of those prepared to pay more than 10 per cent of their weekly income indicated that they would also take special steps to fund the treatment if necessary.

Discussion

The objective of the study was to establish the value which parents of short children put on treatment with growth hormone. On the whole the parents appear to have answered realistically in relation to their own resources. There was a sharp gradient in responses between parents with low incomes and those with high incomes.

In general, parents with lower incomes said they would be prepared to give between 1 per cent and 10 per cent of their income towards the cost. This represented an average contribution of between £1 and £10. The actual cost of growth hormone is upwards of about £100 per week, depending on the age of the child, so that the low earners' 'willingness to pay' represents only a small proportion of the actual cost of treatment. Nevertheless, a willingness to pay up to £10 out of a weekly income of £100 to £150 suggests that these parents do put a substantial value on the treatment. Nevertheless, almost 20 per cent of this income group said they would not be prepared to contribute to the cost of treatment.

For the highest income group, with family incomes after tax of over £500 per week, almost 40 per cent of parents said that they would be prepared to devote more than 30 per cent of their income for their children to receive the treatment. Only 3 per cent were not prepared to pay anything. In monetary terms, the picture for this income group was less clear-cut, with the majority of answers ranging between £10 per week to more than £75 per week. Just over 20 per cent were in the latter category. Thus, as Figure 3 showed, the high income group were 'less generous' in money terms than when they thought in terms of a percentage of their income.

Finally, when asked whether they would be prepared to take special steps, such as taking out a second mortgage or selling their car, in order to pay for their child's treatment, almost 80 per cent responded positively. These positive responses were spread evenly between parents in relation to the proportion of their income they would be prepared to contribute. Thus, these 'special steps' were clearly supplementary to contributions from weekly income, rather than a substitute for them. To some extent this contradicted the reason which parents at the first pilot meeting gave for including the question: they had suggested that those unable to pay might take special steps instead in order to finance the treatment.

Percentage of income prepared to pay for treatment

Income	Total	Nil	1-5	5-10	11-20	21-30	>30
<100	8	2	2	2	1	0	1
101-150	21	4	7	6	3	1	0
151-200	27	2	10	9	5	0	1
201-300	42	3	10	16	6	5	2
301-500	55	4	6	19	9	8	9
>500	29	1	5	5	4	3	11
Total	182	16	40	57	28	17	24

Figure 1 Percentage of income families are prepared to pay for treatment

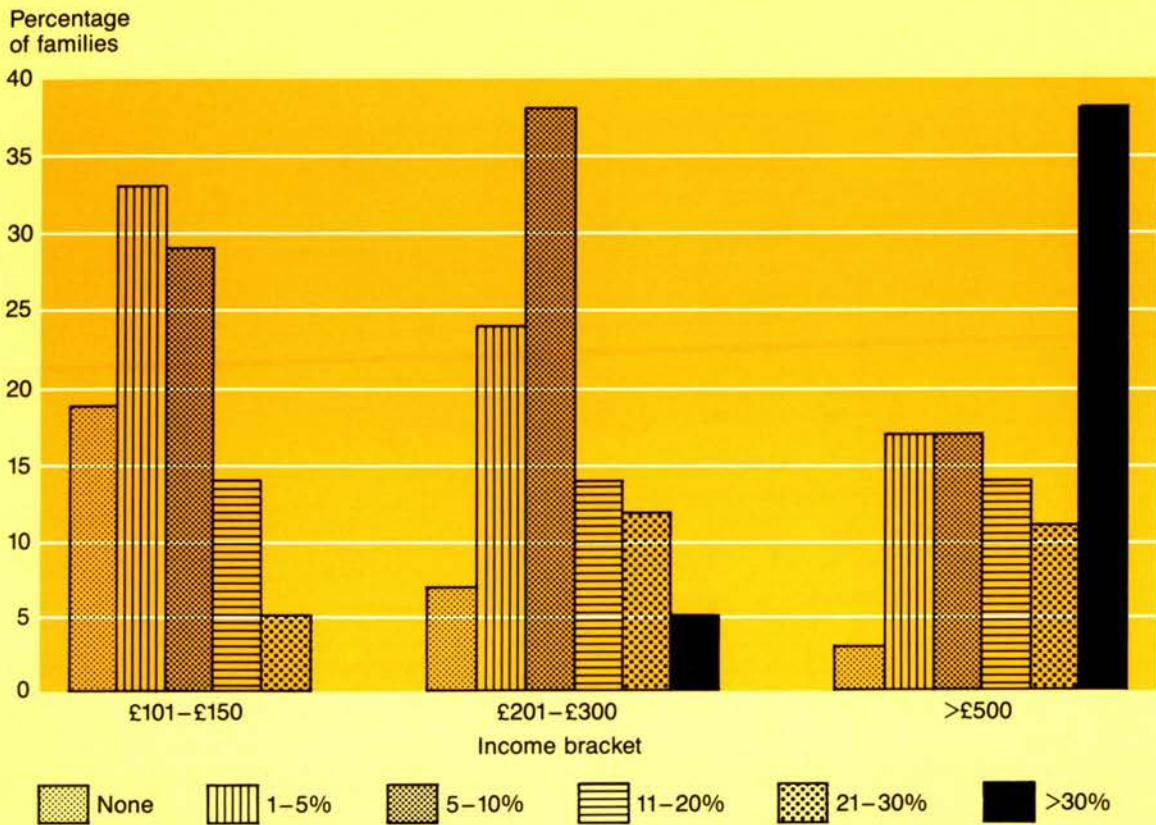


Table The total sample consisted of 182 families, however, 17 of the early questionnaires did not include question 4 and two respondents did not answer this question—thus, question 4 consists of 163 responses.

<i>Amount of income prepared to pay for treatment; £</i>											<i>Willingness to take special steps</i>	
Nil	<5	5-10	11-20	21-30	31-50	51-75	76-100	101-150	151-200	>200	YES	NO
2	1	3	2	0	0	0	0	0	0	0	4	4
4	5	7	4	1	0	0	0	0	0	0	10	8
2	3	11	7	2	0	2	0	0	0	0	18	6
3	3	6	12	9	3	3	2	1	0	0	34	5
4	0	4	5	14	8	4	6	5	1	4	42	11
1	0	0	2	5	7	0	2	5	0	7	18	3
16	12	31	32	31	18	9	10	11	1	11	126	37

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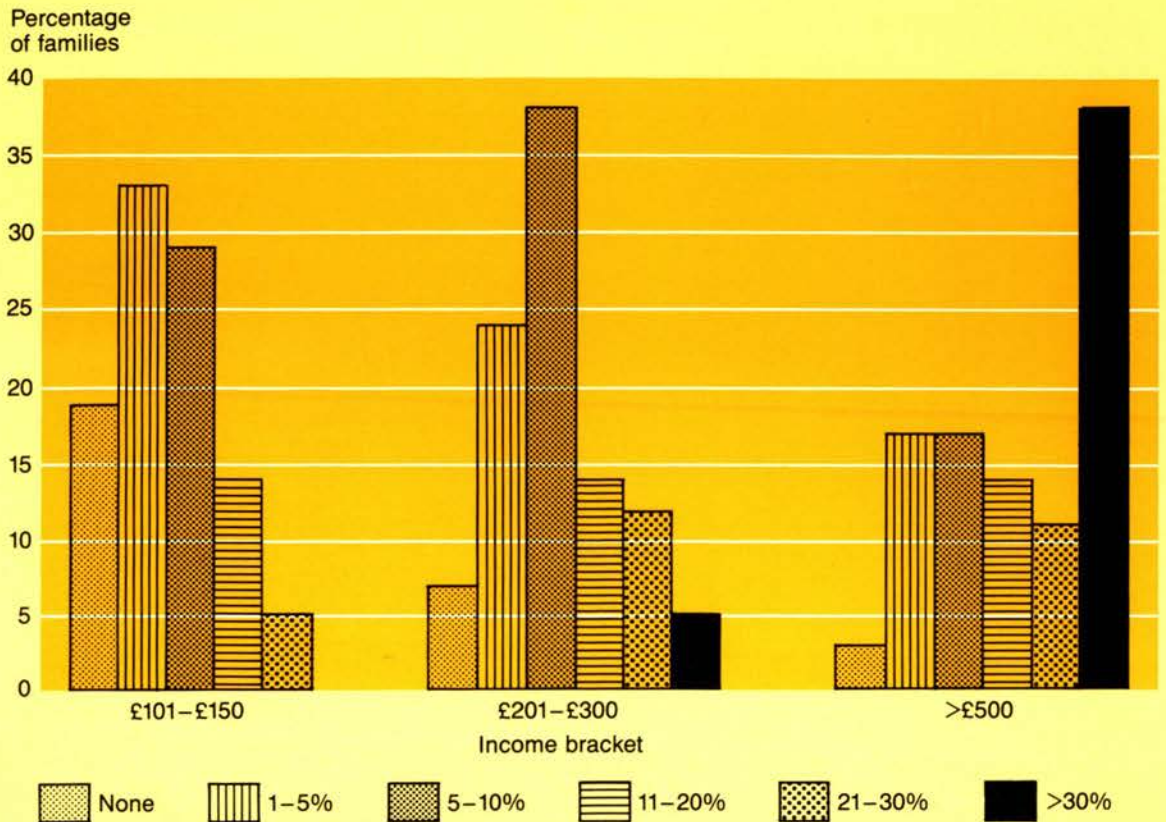


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	<i>Amount of income prepared to pay for treatment; £</i>											<i>Willingness to take special steps</i>	
	Nil	<5	5-10	11-20	21-30	31-50	51-75	76-100	101-150	151-200	>200	YES	NO
30													
1	2	1	3	2	0	0	0	0	0	0	0	4	4
0	4	5	7	4	1	0	0	0	0	0	0	10	8
1	2	3	11	7	2	0	2	0	0	0	0	18	6
2	3	3	6	12	9	3	3	2	1	0	0	34	5
9	4	0	4	5	14	8	4	6	5	1	4	42	11
11	1	0	0	2	5	7	0	2	5	0	7	18	3
24	16	12	31	32	31	18	9	10	11	1	11	126	37

Figure 2 Amount families are prepared to pay weekly for treatment

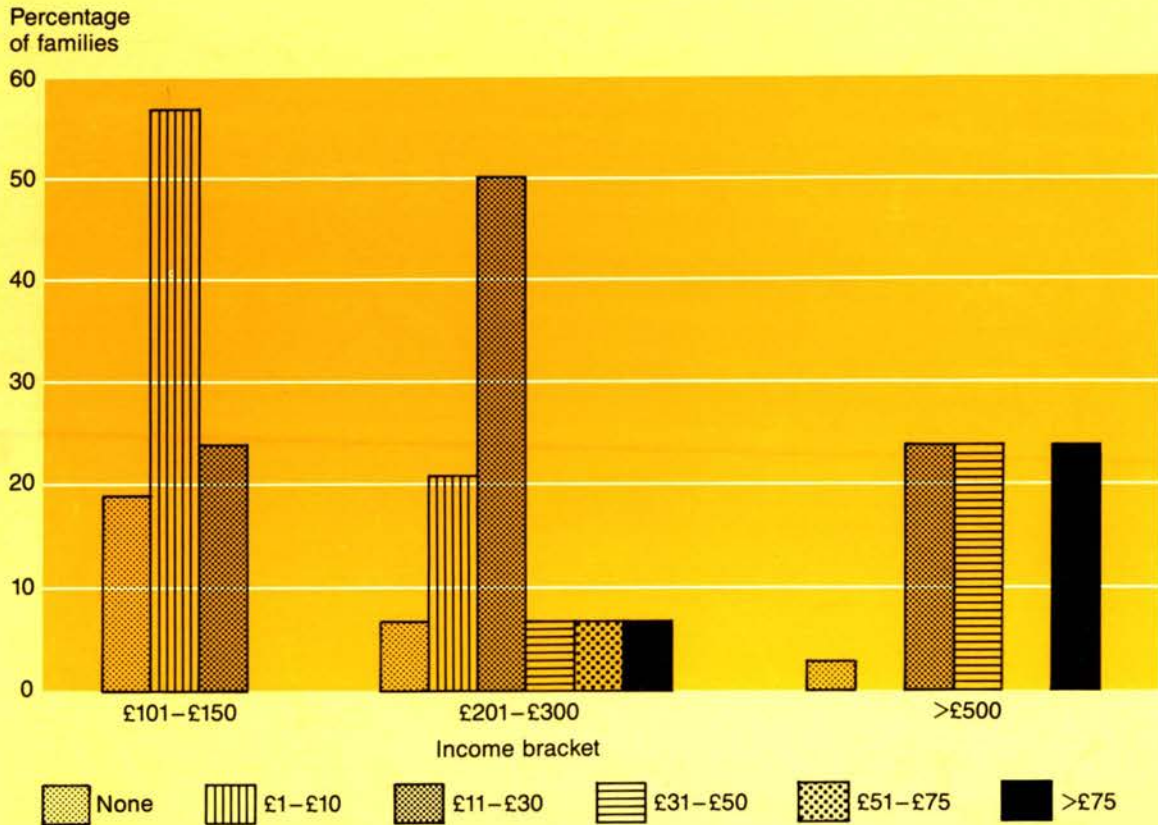


Figure 3 Percentage of income prepared to pay against amount prepared to pay

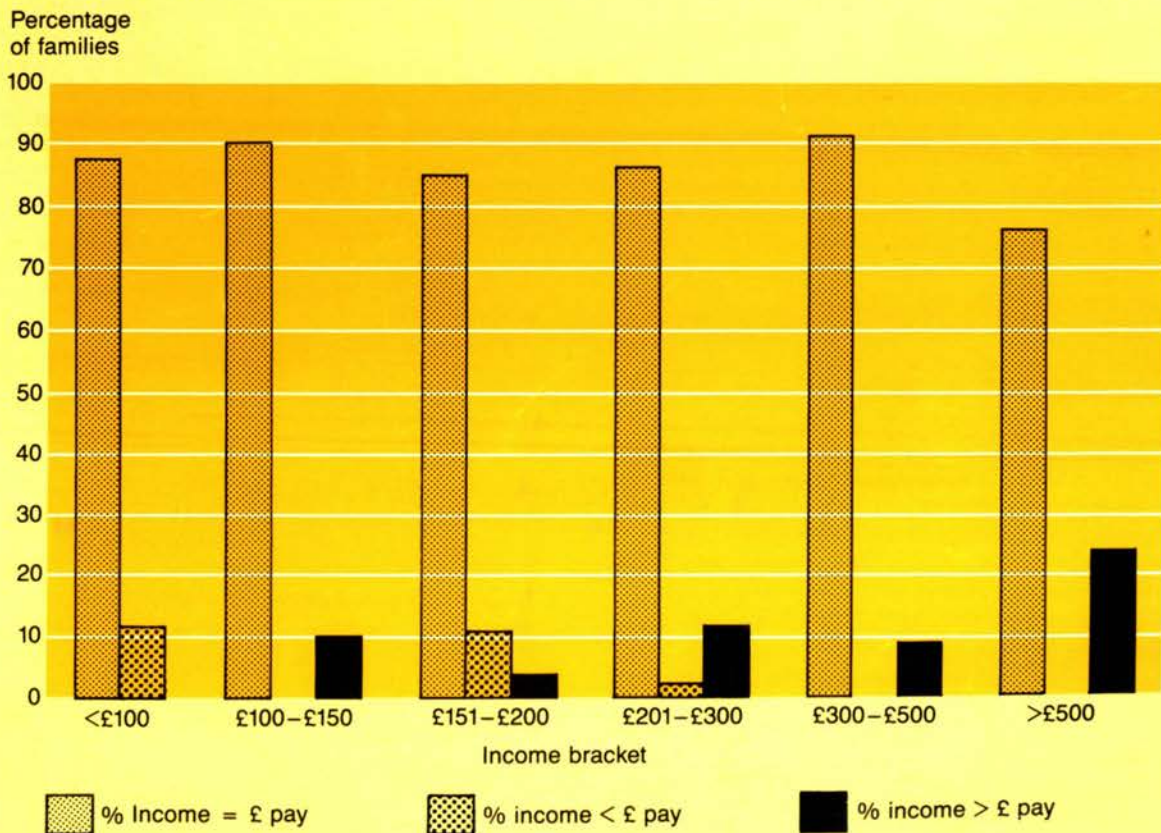
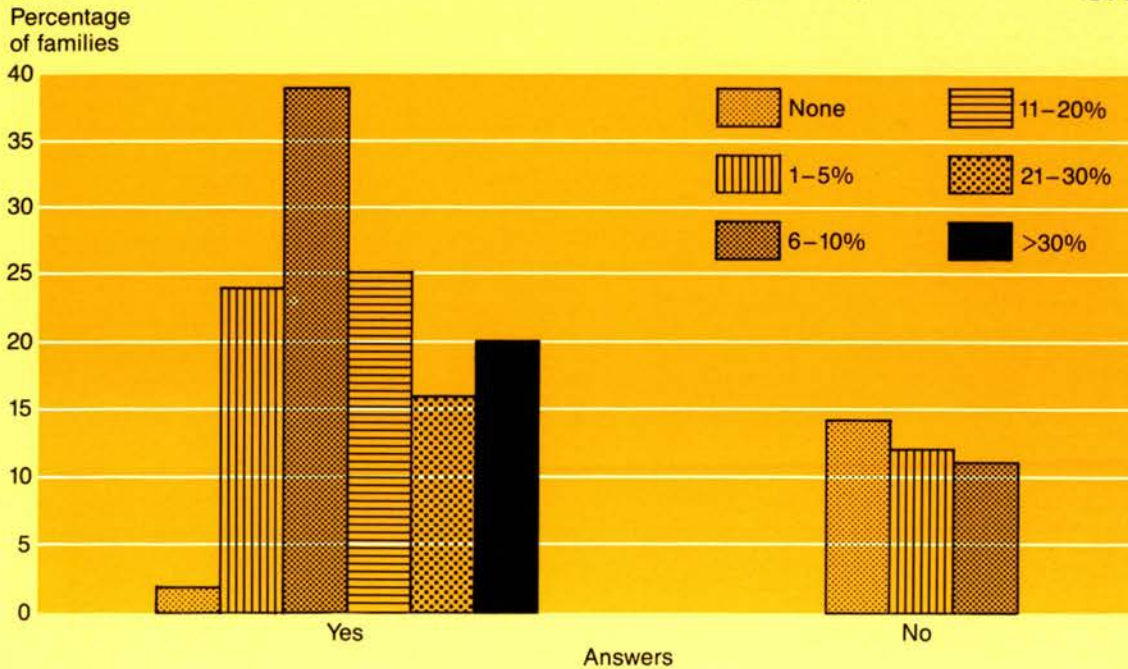


Figure 4 Percentage of weekly income prepared to pay against 'special' step answers



There is no easy way to interpret these results overall, except to conclude that a large proportion of parents do indeed put a high value on the treatment which their child is receiving, at least in relation to their actual ability to pay. Low income groups are prepared to make a substantial sacrifice, and 40 per cent of the highest income group state that they would be prepared to pay a proportion of their income which would probably meet the total cost of the treatment.

In order to put the value placed on growth hormone into perspective, it would be necessary to carry out similar studies for other alternative uses of health service resources. It would also be interesting in a future study to relate parents' willingness to pay to the extent to which their individual child is expected to be below average height. There may also be differences in families' enthusiasm for the treatment for male and for female children or for an only child. Meantime, it can only be concluded that growth hormone is considered to be of very substantial value by a large proportion of parents whose children are receiving the treatment.

This is reinforced by some individual comments written on to the forms or sent with them. For example one set of grandparents who were therefore not eligible to complete the form commented that 'we do however feel very strongly that it would be a crime if growth hormone treatment were discontinued and we would go to the limit of our resources to ensure a child of ours could reach a height a little nearer what is considered normal'. Another parent who did not complete the form simply stated 'If we could pay for treatment we would: I would sell or do anything to ensure our son's continued treatment which is vital'. Another disabled parent who said they could contribute nothing said 'If growth hormone on the NHS is stopped I will personally camp outside No.10 until Mr Major acknowledges this is a necessity.'

One parent who said they would take special steps to fund the treatment said 'In fact owning one's house, car, etc., seem of little importance compared with what growth hormone has done for our son'. Finally, another disabled parent who said they would pay nothing commented 'I do not value his treatment as nothing—I

care very much—I am not in a position to pay. I wish to God I were'.

Above all, the study confirms that the 'willingness to pay' method of valuing health service therapies does appear to yield realistic results in relation to people's ability to make a contribution to the cost of their family's treatment. Even though the sample for this study may have been selectively enthusiastic for the availability of the treatment, they did not give answers which appeared unrealistic in relation to their actual ability to contribute to the cost of therapy.

References

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- Galler H P. The willingness-to-pay approach: caveats to biased application, In Laaser U, Rocella E J, Rosenfeld J B, Wenzel H (Eds) *Cost and benefits and health care and prevention*. Springer-Verlag, Berlin, 1991.

Office of Health Economics

The Office of Health Economics was founded in 1962 by the Association of the British Pharmaceutical Industry. Its terms of references are:

- To undertake research on the economic aspects of medical care.

- To investigate other health and social problems.

- To collect data from other countries.

- To publish results, data and conclusions relevant to the above.

The Office of Health Economics welcomes financial support and discussion on research problems with any persons or bodies interested in its work.

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CONFIDENTIAL**GROWTH HORMONE SURVEY**

PLEASE READ ALL THE QUESTIONS ON THE ATTACHED QUESTIONNAIRE BEFORE ANSWERING. YOUR ANSWER TO QUESTION THREE WILL RESULT FROM YOUR ANSWERS TO QUESTION ONE AND TWO.

The British Government has repeatedly given assurances that Growth Hormone for children who need it will continue to be available free on the National Health Service. We have to accept these assurances.

However, in some other countries families have themselves to pay for the growth hormone for their child. If you lived in one of those countries the questions on the attached sheet ask you to state what proportion of your total family income you would be prepared to pay in order for your child to have the hormone.

Please make sure that your answers to the questions are realistic taking account of your necessary spending on the mortgage, rent, food etc.

Question Four takes account of the fact that you might be prepared to take special steps for your child to be able to get the treatment in addition to what you could pay out of your normal income.

When completed, please return the questionnaire to:

Professor George Teeling Smith,
Health Economics Research Group,
Brunel University,
UXBRIDGE,
Middx, UB8 3PH

using the enclosed stamped and addressed envelope.

Your answer is entirely confidential: We have no method of knowing either your name or address

QUESTIONNAIRE**QUESTION 1**

Out of each £1 of family income, would you be prepared to pay:

PLEASE TICK ONE BOX ONLY

NOTHING → 5p TO 10p → 21p TO 30p →
1p TO 5p → 11p TO 20p → MORE THAN →
30p

QUESTION 2

What is your average weekly income after tax for the whole family now?

PLEASE TICK ONE BOX ONLY

LESS THAN £100 → £151 TO £200 → £301 TO £500 →
£101 TO £150 → £201 TO £300 → OVER £500 →

QUESTION 3

This means that you would be prepared to pay for growth hormone the following amount weekly:

PLEASE TICK ONE BOX ONLY

NOTHING → £21 TO £30 → £101 TO £150 →
LESS THAN £5 → £31 TO £50 → £151 TO £200 →
£5 TO £10 → £51 TO £75 → OVER £200 →
£11 TO £20 → £76 TO £100 →

Your answer to this question should tie up with your answers to questions 1 and 2.

QUESTION 4

If you were unable to pay for your child's Growth Hormone Treatment out of normal income would you be prepared to take special steps to find the money (eg., take out a second mortgage; move to a smaller house; sell your car; take a second job etc)?

PLEASE TICK ONE BOX ONLY

YES → NO →