LETTERS TO THE EDITOR

Patient knowledge and compliance with growth hormone treatment

EDITOR,—There is no direct method of assessing compliance to natural sequence human growth hormone treatment and even urinary growth hormone measurements have proved unsuccessful.[1] What information is available concerns older treatment regimens of intramuscular injections which, not surprisingly, were unpopular with most patients because of pain.[2] More recently Brook and colleagues at the Middlesex Hospital have described their experience of compliance to subcutaneous growth hormone injections with disappointing results.[3]

We have recently reviewed the treatment of 107 (56 boys, 51 girls) consecutive children receiving daily subcutaneous growth hormone injections at the Hospital for Sick Children, Great Ormond Street (n=85) and associated peripatetic clinics (n=22). Mean age was 10·5 years. All patients were interviewed in the presence of a growth research nurse (LM or MM) during the first three months of 1992.

Interestingly only 68% accurately knew their diagnosis, mainly because of the understandable confusion of patients receiving growth hormone treatment, believing they were growth hormone insufficient; 32% of our patient group had low birthweight syndromes, skeletal dysplasias, or Turner's syndrome and were growth hormone sufficient. Understanding of the growth hormone treatment regimen, in all its aspects, was recorded in 93% of patients at Great Ormond Street and 95% of patients at peripatetic clinics. This was surprising compared with the Middlesex group's result of only 48%.[3] Half of our patients were taught their injection technique at home, although many were in consultation with one of our growth research nurses. Using such an approach 76% of patients/parents took on full responsibility for their injections within seven days. A tenth admitted missing three or more injections per month and 20% remembered receiving teaching by a growth research nurse during the previous year. Altogether 62% remembered having a dose change during the last year, although a calculation of dose is made on a surface area basis for all our patients at yearly intervals to determine if a change is required.

We appreciate that knowledge of injection technique does not necessarily equate with compliance, especially during the pubertal age range. However education is one aspect of treatment which can be improved,[4] whereas compliance is much more difficult to influence. We suggest that a major factor accounting for the adequate knowledge of the treatment regimen was the involvement of a research nurse in our growth clinics for the previous six years. It is probable that our results are representative of patients/parents being given a relatively free choice of injection devices,[5] which may directly improve compliance and thereby growth response.[6] Moreover we believe that attention to teaching with the involvement of a dedicated growth research nurse is essential to optimise acceptance of long term daily injection regimens.

R STANHOPE
L MOYLE
M MACSWINEY
The Medical Unit, Institute of Child Health, 30 Guilford Street, London WC1N 1EH

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Audit of screening for congenital hypothyroidism

EDITOR,—Pharoah and Madden conclude that administrative deficiencies were predominantly responsible for inefficiencies of the screening programme.[1] We are currently auditing the neonatal screening programme in the South East Thames region and would like to make the following points:

(1) One of the most important features of well run screening programmes is ownership of the programme. At present in many districts the opposite appears true. The programme involves several health care practitioners at different stages of the programme (for example midwives, health visitors, paediatricians, and community paediatricians) but in many districts there is no one person nominated as responsible for the whole programme. In our survey of health professionals in all districts it appears that only 7% (one of 15) districts in our region had a nominated person in charge of the programme. Nominating named individuals with overall responsibility for monitoring the programme (similar to immunisation coordinators) could improve administrative problems.

(2) A particular problem in inner city districts not mentioned in the report is the difficulty of matching up children when different surnames are given to different recorders or when first names and surnames are muddled. In two districts that we have investigated the problem of 'alternative' surnames resulted in a failure to match 18% (318/1745) of cases initially. Cards could be designed so that mother's surname and father's surname can both be entered separately on the card avoiding this difficulty.

(3) Pharoah and Madden suggest that many of the problems of under and over enumeration due to cross boundary flows of births could be addressed by requiring the district of residence to be recorded on the card sent to the laboratory. However, particularly in inner city districts mothers are often highly mobile around the time of birth (for example being rehoused, temporarily staying with parents, giving alternative addresses to allow care in particular hospitals, etc). Rapid regular monitoring of unmatched results and babies without results may help to identify movement problems. Allocation of NHS numbers at birth (rather than at registration) could resolve this problem.

(4) Finally the authors recommend that regional screening programmes should undertake audits of the stages involved in the screening programme by setting standards for the various stages in the process, comparing practice with these standards, and implementing change as needed. In liaison with the directors of screening laboratories in SE Thames Region we have set operational process standards for many of the steps involved and would be happy to share them with any interested party.

ALLISON STREETLY
CAROL GRANT
GRAHAM BICKLER
Department of Public Health, South East London Commissioning Agency, Mary Sheridan House, 15 St Thomas Street, London SE1 9RY

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Continuous infusion of zidovudine in HIV related thrombocytopenia

EDITOR,—Continuous intravenous infusion of zidovudine was beneficial in children with symptomatic HIV infection.[1] However clinical trials investigated only oral treatment and none compared the oral and intravenous routes of administration. Here we report that HIV related thrombocytopenia, and other related symptoms developing while oral treatment was administrated, may be corrected by continuous infusion of the drug.

Case report

A patient developed a symptomatic HIV infection at 4 months of age with hepatosplenomegaly, failure to thrive, and recurrent bacterial infections as the main symptoms. CD4 cell count was $0{\cdot}130\times10^9$/l and the proliferative response to mitogens was depressed. Clinical and immunological improvement (CD4: $0{\cdot}450\times10^9$/l) was achieved by 150 mg/m²/6 hours of oral zidovudine (daily dose: 24 mg/kg). At 12 months of age the child presented with haemorrhagic symptoms and a platelet count of 10×10^9/l. Platelet bound IgG reactive with specific glycoproteins (gpIIb-gpIIIa) and circulating platelet antibodies were detected. The number of megakaryocytes was normal. Symptomatic thrombocytopenia persisted despite immunoglobulin treatment. A response was obtained with high doses of oral prednisolone (2 mg/kg/day), but several relapses were observed as soon as the dose was slowly tapered off. At 18 months of age a continuous infusion of zidovudine, 1 mg/kg/hour, was initiated via a catheter using a lightweight portable infusion pump and administered over one year (figure). An overall clinical improvement was noted with regression of the hepatosplenomegaly. The platelet counts remained within normal values despite the discontinuation of the steroid treatment. In addition, immunological tests initially improved and P24 antigen became undetectable. The continuous infusion was well tolerated without neutropenia or