the present stage—which entailed the design, synthesis, and screening of over 70 chelators in vitro and in vivo and the identification of several other promising 1-substituted-2-alkyl-3-hydroxypyrid-4-one derivatives similar to L1—took nine years.⁸ The absence of side effects in over 20 patients and volunteers who received L1 18 months ago, some for up to three months and at doses of up to 8 g (4 × 2 g) in a day, suggests that the drug has a high degree of safety when therapeutic doses are given long term.

Despite the above results and the recent discovery of a new method of synthesis of L1 and related derivatives, which will make them about 50 times cheaper than desferrioxamine,³ pharmaceutical companies may become fully interested in orphan drugs such as L1 only after scientists carry out most of the work required for licensing, including both toxicological and clinical trials. The prospect of fully developing L1 and related chelators will also improve if other uses, such as the treatment of aluminium overload, are taken into account. It is highly likely with further positive results from our expanding and continuous clinical trials that L1, and possibly other related oral drugs, will be available for the treatment of patients with thalassaemia within the next few years.

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Outpatients

SIR,—The article by Mr M Duncan and others (30 April, p 1247) makes sorry reading. I have carried out a similar study of the efficiency of the outpatient service in the department of internal medicine in this hospital.

We use three or four consulting rooms, where the patients are seen initially by a junior member of staff. The professor moves from room to room, where he is given a summary of the problem and a plan of management. Thus he sees every patient. This system also provides a useful educational forum and avoids interval time as defined by Mr Duncan and others. In their study this accounted for 25% of the total clinic time.

Since January, basing my calculations on 13 sessions, an average of 25.1 (SD 3.46) patients were seen at each session, of whom 25% were new referrals. Each session lasted 286 (20) minutes, and thus the patient-doctor contact was 11.4 minutes—some 50% longer than in the authors' study. Altogether 327 patients were seen. In not one instance were notes or relevant clinical data missing.

This department, with responsibility for 60 beds, has three full time medical secretaries and

one records clerk. The secretaries are paid Frs 5000-6500 monthly and the clerk about Frs 4500-6000 (before tax). In the private sector they might command up to 50% more. I support Mr Duncan and his colleagues in their conclusion that these staff play a vital role in the efficient working of outpatient departments but suggest that useful alterations might be made in the manner in which these sessions are run.

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Care of physically handicapped young adults

SIR,—Dr Martin C O Bax and others (23 April, p 1153) are to be congratulated on their study of the needs of handicapped young adults. Support does not necessarily require specific teams as is shown by the following case report.

A 44 year old divorced woman is quadriplegic as a result of multiple sclerosis and depends on others for turning in bed, transfers, washing, dressing, feeding, and all household tasks. Specific help is needed for bladder and bowel functions. Her mental state is normal, and there is no evidence of intellectual or cranial nerve involvement in the disease. She lives with her daughter in an extensively modified council house.

In 1980 she developed a large ischial pressure sore. By 1981 she was needing about 80 hours' care each week by the community nurses (including two calls nightly) and social services. Stress among these professionals was increasingly apparent, and interprofessional problems occurred almost daily.

Case conferences with senior representatives of all the professions concerned confirmed a commitment to maintain the mother and daughter in the community and avoid residential care for the mother and foster care for the daughter. Close liaison between the care attendants and community nurses ensured that the patient was not left alone for more than three hours. This overcame the isolation which had resulted in her making excessive demands on nursing time. A low air loss bed was provided, avoiding the need for readmission to hospital for pressure care over the six years of follow up.

Who does what?

Care attendant

Meals, transfers from chair to bed and back, hair washing, emptying urine bag, help with washing, sewing, mending, writing letters, dressing

Home care worker

Cleaning house, laundry, shopping, and paying bills

Community nursing

Specific nursing care for pressure sores, catheter and bowel care, and bathing

Social worker

Counselling

Disabled living adviser (occupational therapist)

Advice on practical changes in the environment—for example, Possum

Adaptation technician

Minor alterations to home

Domiciliary physiotherapist

Maintenance of level of function, management of spasticity

Hospital

Support for community services when needed

General practitioner

Continuing personal care

It has been estimated that between 1968 and 1986 the health and social services capital costs exceeded £30 000, and the costs for 1986-7 were at least £330 each week.¹

This woman obtains her community support from the pool of domiciliary workers (see box) and not from a specific team. The willingness of the medical staff to work with the social services management,² the production and monitoring of a plan by multiprofessional conferences,^{3,5} the presence of a health service equipment budget to support people in the community and the devolution of many care tasks from the community nurses to social services workers⁶ were important features of her care. This patient has provided a model for the development of community care for severely physically handicapped people in Harrow.

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Diagnosing Marfan's syndrome

SIR,—I agree with Dr Maurice Super (14 May, p 1347) that the main reason for diagnosing Marfan's syndrome is to offer screening by echocardiography for the one fatal complication—aortic aneurysm, which can rupture or dissect with an 80% mortality rate. Elective replacement of the aneurysm with a dacron graft has a 5% mortality rate with an 87% survival rate after five years of follow up.¹ This operation is offered when the aortic root diameter reaches 5 or 6 cm, but the family history must be taken into account. We have advised surgery at an aortic root diameter of 4.4 cm in an affected daughter with severe unexplained chest pain whose father had died suddenly of aortic dissection at that precise aortic diameter.

When can you make a diagnosis of Marfan's syndrome? The consensus of opinion seems to be when two of three systems (eye, heart, and skeleton) are classically affected. Preferably there should also be a positive family history. The most common diagnostic errors such as dominantly inherited mitral valve prolapse with marfanoid habitus (in the absence of aortic root dilatation)² and joint hypermobility syndrome with marfanoid habitus³ are thus avoided. Dr Super's suggested scoring of major and minor criteria would make an erroneous diagnosis of Marfan's syndrome in both these instances and in mild, dominantly inherited Ehlers-Danlos syndrome type IV.⁴

If a patient over 20 years of age has a normal echocardiogram the longterm prognosis is excellent, and a letter stating this should help to obtain reasonably priced insurance and mortgages. When the diagnosis is in doubt records should never contain reference to Marfan's syndrome but rather to a marfanoid condition, even though regular surveillance may be continued until the diagnosis is certain. Ocular, skeletal, and major cardiovascular complications should have developed by age 18, and in their absence the family can be counselled that this is not Marfan's syndrome and that the prognosis is good.

The Marfan Association has 450 member families

and offers support and information to newly diagnosed families through 14 support groups in the United Kingdom. It also provides a database for investigators interested in research into the cause and treatment of the syndrome. Marfan's syndrome should be diagnosed as all aspects of it are now treatable although not yet curable.

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Vocational training in general practice

SIR,—In her letter (28 May, p 1534) Dr Dorothy M B Ward has ignored our questioning of the strategy of the Joint Committee on Postgraduate Training in dealing with the allegedly recalcitrant behaviour of the North East Thames region in favour of a discourse on the grounds on which the decision was based. As Dr John Sinson also calls for the evidence to be examined we would be happy to clarify this aspect.

As Dr Ward states, the decision was not based solely on the 1987 report but on the region's alleged failure to implement stricter criteria for selecting trainers after criticisms made in the 1985 visit. In 1987 two practices failed to meet the required criteria. These facts are not in dispute.

In the 1987 report this sentence appears: "We are very much aware that we have only seen five out of the fifteen practices . . . and that these were deliberately chosen, as the visitors had requested, to include those about which the regional adviser was particularly concerned" (our italics).

The report then states that of these five practices, two were above average, one was approved with reservations, and two should not be reappointed. Unsurprisingly, these were the two specifically selected as giving cause for concern.

Neither of these trainers had, however, undergone the reselection process within the preceding three or four years. It therefore seems quite illogical to use them to exemplify the region's compliance or otherwise with the recommendations made in 1985. If, as Dr Ward implies in her final paragraph, the Joint Committee on Postgraduate Training thought that this was the main point at issue and that the 1987 visit was in the nature of a final test, with disciplinary rather than "advisory and educational" connotations, then (a) this fact should have been made explicit, in advance and in writing, to those being visited and (b) rather than taking a small, deliberately biased sample the committee should have insisted on examining a significant number of training practices approved or reapproved since 1985 to determine whether these conformed to the required criteria. There could then have been no argument about the fairness of the procedure or the verdict.

Instead, the adopted strategy—of first inviting the district to identify its most problematic training practices and then using these as the basis for a judgment on the entire region—might appear to a cynical observer to be a deliberate set up, into which the region's officers were naïve enough to walk. More charitably, it could be regarded as just one further instance of the failure of

communication that has characterised the entire episode.

Until this time visits by the committee had, indeed, been regarded as "advisory and educational." The committee must now choose whether its visitors are to be educational advisers or policemen—they cannot simultaneously be both. And those on the receiving end are entitled to know which of the two they are entertaining.

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Breast milk and HIV infection

SIR,—We have received a letter from the chief medical officer at the DHSS to all doctors on the subject of human immunodeficiency virus infection, breast feeding, and human milk banking. He advises a number of specific steps that should be taken before using bank milk. He states his "confidence that future mothers will accept the need to safeguard the vulnerable newborn in every way possible and that they will continue to respond generously to the needs of these babies."

We cannot see how we can continue to run a milk bank if we obey his specific steps. The relation among our special care unit, the local health visitors, and the mothers who help us has created an enormous amount of goodwill. We believe it would be thrown away if we had to ask women who wished to help with breast milk donations whether their husband, or any other man they might have had sex with in the past 10 years, might have had sexual partners who lived in an African country.

We cannot see the logic in having to screen those women who wish to donate milk while not screening all women who book in for maternity care. Blood is often spilled in maternity units, and it seems out of proportion to test those who are offering a secretion which has only a theoretical risk of passing on infection while avoiding testing those who may be a real risk to members of staff and other patients. We have asked the chief medical officer if he will publish the scientific evidence on which he bases his advice.

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Disciplining doctors

SIR,—While welcoming Dr Malcolm Forsythe's article (21 May, p 1421) we disagree with his statement: "As the charge is serious it is usually necessary to suspend a doctor on full pay."

All but one of us have been suspended. We do not know whether we are typical of the 40 doctors each year who are disciplined using HM(61)112, but we think that suspension was neither necessary nor just in our cases, and probably in many more.

Two of us have accepted premature retirement at age 55, and we know of another doctor who has done so at an even earlier age because of ill health precipitated by the attack on his professional position. We think that the extension of the HM(61)112 provisions to community medicine in 1987 has serious implications for public health.

Two of us went to the high court in an attempt to have our suspension lifted. For one of us this did help to decrease the duration of suspension to 15 months. In another case the high court was used

to overturn the decision to dismiss the doctor.¹ Another of us was not suspended but has had her post whittled away after allegations of incompetence in 1979 and now faces redundancy. Her appeal against this to the secretary of state will be heard soon.

The joint Joint Consultants' Committee and DHSS committee reviewing HM(61)112 is taking evidence until the middle of June. Doctors who know of inappropriate or unjust use of this procedure or have suggestions for improvements should write to Mrs K James, Eileen House, 80-94 Newington Causeway SE1.

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Allocating resources

SIR,—Many of our patients are on waiting lists which operate on a first come first served basis. This is an unfair strategy which ignores severity of disease, disability, and urgency. I recently tried to arrange urgent investigations for a 44 year old obese mother of four children who had a recent onset of angina with a normal electrocardiogram. I was told by the senior registrar that the cardiology department was overwhelmed so general practitioners were being asked to treat patients with nitrates and β blockers, advise about diet, measure lipid concentrations, and reassess over the next two months. This is a potentially dangerous delaying tactic and not a sound way to ration exercise electrocardiographic tests.

It would be better if hospital specialists, general practitioners, representatives of community health councils, and local self help groups could come together to select criteria which could be used to allocate priority. In this case relevant factors to consider include family history, duration and severity of symptoms, results of investigations, blood pressure, coexisting diseases, age, dependants, willingness to stop smoking, and so on. A consensus could identify the most relevant factors and these could be weighted to obtain a final score. General practitioners could then be circulated about the need for and use of such a priority system to identify those patients in need of urgent investigation.

The same approach could be used for patients on waiting lists for other investigations and those waiting for bath aids, surgery, and so on. In each case appropriate social, psychological, medical, functional, and epidemiological factors should be identified and agreed by all concerned. There is a danger that if such criteria are drawn up only by hospital staff important factors will be overlooked or incorrectly weighted.

Criteria for allocation of priorities based on needs and risks would have to be regularly reviewed as resource constraints change and new information becomes available. A priority waiting list does not mean that those on the routine list are ignored. Each week a certain percentage of patients could be taken from each list. To have a waiting list policy based on the first come first served principle should be considered unethical. We must develop priorities jointly with consumers and other health professionals which are seen to be fair and explicit in the way that they deal with the allocation of scarce resources.

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