abstinence syndrome is less prolonged and severe.

The true goal is full abstinence and a normal baby, and most important to the future of the family is a trusting relationship between the mother and those caring for her.

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AIDS and medical confidentiality

SIR,—The issue of confidentiality in the context of infection with human immunodeficiency virus (HIV) continues to cause controversy in both the medical and lay press. No one seems to have consulted those affected.

Drs Peter Fisk and Vincent Riley report in their letter (25 July, p 268) that a group of individuals in Leicester "were divided in their views about the confidentiality of information gained in [the] sexually transmitted disease clinic." They did not state to which group the individuals questioned belonged, although they presumably belonged to a group that was in some way perceived as being at high risk for infection with HIV.

In July I undertook a survey of 43 patients with the acquired immune deficiency syndrome (AIDS) attending the Praed Street Clinic at this hospital. Most (32 patients; 74%) were registered with general practitioners, and 25 of these felt that they would rather contact the hospital than their general practitioner if a problem arose, whether it was perceived as being related to HIV infection or not. The reasons given were as follows: confidentiality (50%), lack of experience on the part of the general practitioner (28%), better cover from sexually transmitted diseases clinic in general (14%), and no particular reason (9%).

These results suggest that confidentiality is a major factor in preventing people with AIDS from continuing their relationship with their general practitioner. At a time when the Department of Health and Social Security is trying to develop community resources for people with AIDS and is setting up ways of educating primary care physicians in the management of problems related to HIV infection, it seems sad that the issue of confidentiality remains such a source of doubt for these patients. This survey was conducted in late July, after the BMA conference; one wonders what the impact of the conference was on the results and how we can redeem ourselves as a profession.

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HIV infection: increase in public awareness and anxiety

SIR,—Dr C Sonnex and colleagues (18 July, p 193) present a unique approach to preventive medicine. They set out with the premise that "Those who work with HIV infection have always seen it as being sexually transmitted and thus have been fully aware of the potential heterosexual spread."

During the three month study period 847 patients attended for testing, but roughly a quarter (206) "decided against the test after counselling." More than half of these patients (106) were heterosexual and concerned about previous bisexual partners, prostitutes, or casual girlfriends. The counsellors somehow managed to allay such

anxiety sufficiently to persuade the patients to leave untested. But did they allay their patients' anxieties? I suggest that their worries would have been more expeditiously and thoroughly alleviated by testing, that the counsellors had neither the right nor the knowledge to dissuade them from the purpose of their visit, and that to pursue this approach is inconsistent with the public interest of establishing the transmission risks of the human immunodeficiency virus (HIV).

Having found two heterosexual men to be positive (and no women), the authors conclude that "This is somewhat concerning and emphasises the potential spread into the heterosexual community." One of these men had been misbehaving in Zimbabwe and the other used intravenous drugs. Surely I am not alone in the conviction that this is not science or the proper practice of preventive medicine?

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AUTHORS' REPLY,—We thank Dr Evans for raising an important issue regarding our paper and for providing us with an opportunity to clarify a few points. It is correct that 106 out of 206 attenders who decided against testing for antibodies to HIV after counselling were heterosexual. The table shows, however, that not all of these were concerned about previous bisexual partners, prostitutes, or casual girlfriends; these accounted for only 28.5%, 17.7%, and 18.2% of requests, respectively. We agree with Dr Evans that these patients are unlikely to have their anxieties allayed by counselling, and indeed most of the second and third groups were tested.

With regard to bisexual contact, it was interesting that on further questioning many women began to doubt whether past boyfriends had in fact been bisexual. After discussion, not dissuasion, many of this group decided against testing. In addition, some people were not tested when they attended if their risk contact had been recent because of the delay between infection with HIV and the development of antibodies. We apologise for not making this point clear. An important statement not quoted by Dr Evans was that most heterosexuals not tested "were at minimal risk of exposure and showed disproportionate anxiety about AIDS owing to lack of knowledge about HIV infection." These were alluded to in the "miscellaneous" category at the foot of the table and comprised those who had social contact with high risk groups, those who had suffered insect bites while travelling abroad, etc. We are confident that our counsellors have the "knowledge to dissuade" this group "from the purpose of their visit," but dissuasion is rarely used. It has always been the policy of this clinic to test anyone wishing to know their HIV antibody state. Our counsellors provide information from which the individual concerned can make a decision whether to be tested.

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SIR,—Dr C Sonnex and coworkers (18 July, p 193) show that the publicity campaigns about the acquired immune deficiency syndrome (AIDS) were successful in motivating men and women to attend for screening. We report on another desirable aspect of the recent media events concerned with AIDS.

We reviewed the case records of new and existing patients who attended our clinic during

March 1987 (during and soon after the week of media coverage on AIDS). A total of 1193 patients (692 men and 501 women) were seen, 70% of whom were new patients. Though this amounted to a 34% increase in attendance over March 1986, only a modest increase (9%) was evident over February 1987, and a fall of 17% occurred in April 1987, after the media campaign.

The human immunodeficiency virus (HIV) antibody test was requested by 173 men (25%) and 101 women (20%). Of the 102 men and 61 women who decided to have the test, only three men (all homosexual) were positive. All of the patients who requested the test were offered counselling and screening for other sexually transmitted diseases.

A reason for seeking the test was given by 79 men (30 homosexual, 10 bisexual, 17 several heterosexual partners, 12 intercourse with prostitutes, three drug abusers, and seven miscellaneous reasons) and 57 women (16 consort bisexual, 16 sex with several partners, nine consort promiscuous, three consort drug abuser, three history of blood transfusions, and 10 miscellaneous reasons).

Though three men (1.7%) and 27 women (27%) declined screening for sexually transmitted diseases, a new condition was diagnosed in 23 men (13%) and 24 women (24%). Of the six cytological abnormalities detected, one was reported as "positive, severe dyskaryosis with warty atypia." Colposcopy and biopsy confirmed the diagnosis of cervical intraepithelial neoplasia stage III, which was treated by laser vaporisation. This patient had had intercourse with a drug abuser nine months previously and had attended purely to have a test for HIV. The table summarises the results.

Number (percentage) of new conditions diagnosed in those presenting for HIV tests during March 1987

Diagnosis	Men (n=173)	Women (n=101)
Total No of new conditions	23 (13)	24 (24)
Chlamydial infection	3 (1.7)	6 (6)
Non-gonococcal urethritis*	6 (4)	—
Trichomonal infection	—	1 (1)
Warts	8 (5)	1 (1)
Gonorrhoea	1 (1)	0
Tinea cruris/bacterial vaginosis	2 (1)	4 (4)
Abnormal cervical cytology	—	6 (6)
Balanitis/candidiasis	3 (2)	6 (6)
Hepatitis B markers	14 (8)	2 (2)
Syphilis markers	9 (5)	0

*Other than those with positive cultures for *Chlamydia trachomatis*.

Some of the patients requesting the test would probably have attended even in the absence of a publicity campaign. Nevertheless, we are confident that the campaign helped in uncovering new conditions that would otherwise have been missed. Thus in spite of the increase in workload we believe that whenever possible all those who present for tests for HIV (whether high risk or not) should be persuaded to have screening tests for other sexually transmitted diseases.

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AIDS and insurance

SIR,—Problems encountered in obtaining life insurance as discussed in Medical News (22 August, p 507) are a favourite topic of those who counsel patients with the acquired immune

deficiency syndrome (AIDS) and others concerned in the AIDS industry.

There seems, however, to be some muddled thinking about this matter. A life insurance policy is not another aspect of state funded social security but a straightforward financial transaction. In the past it was understood that an application for an insurance policy, even for a few hundred pounds, would necessitate a full medical examination. If some life shortening condition was found it was equally understood that cover might be refused or accepted only on increased terms. I assume that a detailed medical examination has been found to be uneconomical for smaller policies, but, presumably, this does not imply the right to defraud the company.

In discussing the test for antibodies to the human immunodeficiency virus (HIV), some counsellors have been suggesting that the subject should seek (perhaps additional) life insurance before the blood test is performed. This is surely no more ethical than advising an overweight 40 year old man with polydipsia to increase his life insurance before his fasting blood glucose concentration is investigated.

Life insurance companies owe it to their shareholders and policyholders (particularly those holding "with profit" policies) to take all possible care to exclude poor risk lives—for whatever reason. We keep hearing of the "rights" of various groups in our society. A carrier of HIV antibodies has every right to advice, civilised handling at all times, and, when necessary, full medical treatment. He or she does not have the right to cheat insurance companies.

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Infantile apnoea and home monitoring

SIR,—Dr Peter G F Swift's letter (11 July, p 118) about infantile apnoea and home monitoring clearly reflects his belief in the value of alarms. We agree that alarms may be useful in selected patients (and parents), but some points need clarification. Children have died while being monitored despite the alarm responding,¹ and, as Dr Swift says, this must be explained to the parents. Though Dr Swift has encountered no deaths during home monitoring so far, Emery *et al* have already pointed out that it will still take over 100 years to prove scientifically whether apnoea alarms save lives.²

Dr D M Reid (p 119) correctly reminds us that for parents scientific proof is not the only issue. Nevertheless, Dr Swift's statement that monitors "helped many parents to sleep, reduced overt anxiety, and improved parent-child interaction" must be challenged, particularly as five families subsequently declined a second monitor. No monitor is trouble free, and comprehensive support arrangements must be arranged. Our own experience of 70 monitored children (32 siblings and 38 infants who had experienced severe "apparent life threatening events") showed that almost half of the parents needed to contact the hospital at some time during monitoring for mechanical or medical problems.³ This was despite frequent outpatient and telephone contact, especially during the first weeks of monitoring.

The importance of the National Institutes of Health consensus report is, as Professor Hamish Simpson (30 May, p 1367) states, that for the first time the use of apnoea alarms is considered for other conditions than sudden infant death syndrome.⁴ We welcome this as we believe that it is necessary to analyse the reasons why an alarm is being used. Attacks of lifelessness requiring vigorous or mouth to mouth resuscitation in infants who have suffered severe apparent life threatening

events have a high risk of recurrence (40%) and probably of causing sudden death.^{5,6} All such infants should thus receive a home apnoea alarm.

In our experience, however, most parents of siblings of victims of the sudden infant death syndrome do not need a home alarm. The risks to a sibling have probably been exaggerated in the past.⁷ The syndrome and the use of monitors are fully explained and any parental worries dealt with during pregnancy and before discharge. The child is reviewed regularly, especially around the time of the previous infant's death, and parents of such infants may contact the hospital if they are anxious.

If the parents cannot cope or sleep because of their fear of the sudden infant death syndrome despite our reassurance they are given a monitor. The lack of scientific proof should never deny such parents an alarm, for their sake as much as for the child's. Home monitors are not, however, the perfect answer, and yet many parents now feel guilty if they do not use an alarm "just in case something happens." Dr Swift, in stating that "it is surprising that many paediatricians are reluctant to provide respiratory monitors for use at home," puts similar pressure on paediatricians. Clinical judgment and the lack of local finances for monitors and follow up may mean that the correct decision is not to provide an alarm. The clearest message from the National Institutes of Health is that, despite the difficulties, it is time for scientific evaluation of the monitors and psychological problems related to them so that the correct decisions may be made, based on fact not emotion.

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- 7 Irgeens LM, Skjaerven R, Peterson DR. Prospective assessment of recurrent risk in sudden infant death syndrome siblings. *J Pediatr* 1984;104:349-51.

SIR,—I agree with many of the points raised by Dr Peter G F Swift (11 July, p 118) regarding the possible benefits of home apnoea monitoring in siblings of victims of the sudden infant death syndrome and infants who have suffered previous apnoeic attacks.

Since 1980 we have monitored 288 infants (244 siblings of victims and 44 infants with apnoea) using the monitor described by Dr Swift. Like him, we have found that most families have found monitoring helpful: 28% of the families in which one child has died as a result of the syndrome have requested a second monitor and six families have used a third. Only three families to date have declined a second monitor.

Several points regarding the issuing of home monitors merit further emphasis. It must be explained clearly to all parents that there is absolutely no guarantee of infant survival. In our experience, most parents can accept this. Parents should be shown how to use the monitor, and possible advantages and disadvantages should be clearly explained, preferably before a final decision about monitoring is made. If monitoring is to be undertaken all parents should be instructed in basic resuscitation techniques, and there must be an adequate 24 hour back up service to deal with any problems that may arise.

I would, however, disagree with Dr Swift on one point. There is at least one recorded case,¹ and several anecdotal cases, of death occurring while an infant was being monitored. In our experience this has occurred only once to date, in a sibling of a victim of the sudden infant death syndrome. These parents are currently using a monitor for a subsequent infant and do not in any way regard the monitor as a failure because their previous infant died.

Finally, I would agree wholeheartedly with the comments of Dr David M Reid (11 July, p 119) to the effect that some of the benefits of monitoring may not be easy to assess in scientific publications. I suspect that those who have not lost a child in this way cannot fully appreciate the difficulties faced by parents in handling another baby. In the absence of any investigation that might assure parents that a second infant will not suffer the same fate as its sibling, constant observation is deemed necessary. In my view, if such parents think that an apnoea monitor will help them in caring for their baby one should be provided—that is, the decision should eventually be made by the parents in full knowledge of the facts. I would, however, emphasise that no parents should be talked into using a monitor or be made to feel guilty if they decline one, and the continuing use of a monitor should be seriously questioned if the monitor itself seems to be causing problems.

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- 1 Lewak M. Sudden infant death syndrome in a hospitalised infant on an apnoea monitor. *Pediatrics* 1975;56:196-8.

The myelodysplastic syndromes

SIR,—Drs D M Layton and G J Mufti (25 July, p 227) draw attention to the main features of the myelodysplastic syndromes and the need for further research into new therapeutic strategies. The problem, of course, is that we have only a very limited understanding of the disease processes, which makes our therapeutic choices difficult. It is now generally accepted that the syndromes arise from a premalignant clonal abnormality of a haemopoietic stem cell¹ and that the various clinical manifestations reflect a multistage progression to overt leukaemia.

Treatment may be directed towards suppression or elimination of the abnormal cells or, as Drs Layton and Mufti suggest, to differentiation of the functionally immature preleukaemic cells. It is perhaps worth drawing attention to the potential attractions of tretinoin (retinoic acid) in the management of these conditions. While retinoic acid is well established as a differentiating agent for preleukaemic cell lines in culture,^{2,3} there is an additional rationale for its use. It has been known for some time that retinoids prevent chemically induced skin cancer in mice and other tumours, possibly by interfering with tumour promotion. Retinoic acid can cause regression of experimental premalignant lesions^{4,5} and suppress radiation induced leukaemia in mice, though it is not clear whether this is due to immune stimulation or to a direct effect on the leukaemic cells.⁶ A recent randomised therapeutic trial of isotretinoin (13-*cis* retinoic acid) compared with supportive treatment alone showed that in non-sideroblastic patients with less than 6% blasts in the marrow there was a significant increase in survival at one year in the group who received treatment from 36% to 77%.⁷

This is encouraging, though it remains to be confirmed, but we still have little information about the mode of action or whether there is a longer term benefit in suppression of abnormal