

3, Hengist Close,
Horsham, Sussex.

November 29th, 1968.

Dear

Patrick,

ASBAH.

It is now just under two years since the 1966-67 Committee took the decision to borrow money and to launch ASBAH on the public in the most ambitious way apparently open to them. This operation met with limited success, but it did provide a platform, however small, from which we could move forward in April 1968. There was also a great deal of public sympathy created by the World in Action film and the ITV appeal, as was evidenced by the very considerable number of press-cuttings from local papers which we received at that time.

In my view, there has been a serious loss of impetus since that time, and we have not sufficiently expanded either our operations or our outlook in the meantime. (I must emphasise here that no blame for this can attach to any of our full-time staff. They could only work within the framework we gave them and along the lines we seemed to lay down.)

I feel the time is now ripe for a concise re-statement of the aims the Committee had in mind in 1967, and I have tried to set out such a summary in the attached pages. I am aware that these lists of aims are not exhaustive and there are no doubt important items which I have omitted.

It is quite clear from the attached pages that the expenditures envisaged are colossal. It is also quite clear to me that Public Funds will not be available, in anything like adequate amounts, under the present or any foreseeable future economic circumstances in this country. What we require is a vast, but not unattainable, degree of public support, but we shall not obtain this from the level of publicity we have sought during the past seven months.

I consider the early appointment of a Press Officer or P.R.O. is most urgent - even more urgent than Editorial or Welfare Staff. We also need a comprehensive fund-raising programme, if we are to have any hope of achieving our objects.

In particular, we need the services of a P.R.O. to create a climate in which it becomes the fashionable thing to do to support ASBAH. We also need to undertake the very difficult task of creating fund-raising groups at all levels of society throughout the country - an operation which will probably take two or three years to take effect, given the necessary degree of enterprise at the start, and preferably supported by some novel form of fund-raising as well.

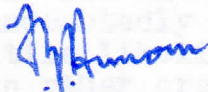
Is there a better moment to begin our efforts towards this than now ?

As I think there is not, I wish to propose the appointment of a Press Officer or P.R.O. at our next Committee Meeting.

I should like to add three things. Firstly, to repeat that our own staff cannot in any way be blamed for our own loss of impetus. Secondly, I am aware that the achievement of any of the attached aims will take time. Thirdly, I am aware that their achievement might be said to be a utopian dream. I do not accept this view, nor do I agree that any of the items listed are unattainable, given the necessary degree of public support.

It was to achieve objects of this kind that I and many others joined the Association. Most of our members are only waiting for ASBAH's Committee to show again the kind of enterprise and ambition we promised in January 1967. If we fail to do so, what will the Spina Bifida and Hydrocephalus Problem be like in ten years' time ?

Yours sincerely,



(Frank Armour)

To All Committee Members (ASBAH)
Mrs. Skellon
Mr. Browning

A. The Medical Needs.

1. Research into Causes.
2. Research into methods of Treatment.
3. Research into problems arising after initial treatment, especially re hydrocephalus and kidney failure,
4. The financial support of the S.B. Research Society and any developments therefrom.
5. Establishment of many more treatment centres.
6. Establishment of centres at which comprehensive follow-up treatment can be made available, with the necessary liaison between specialists.
7. Adequate information channels for Midwives and District Nurses in all areas, to ensure immediate action is taken after birth, and to prevent the giving of disastrously false information and prognoses - or even no information at all.
8. Adequate training and information for physiotherapists and others concerned with the manifold problems arising throughout childhood.

The fact has to be faced that there is no prospect of the Health Service (and present Research Grants) doing more than nibbling at the above requirements. The Health Service cannot maintain its present essential requirements and services, let alone cope with large, new and expensive needs such as ours undoubtedly are. If ASBAH cannot provide vast funds, there seems little likelihood of SB & H receiving the attention we know is needed. No other organisation is likely to do the job for us, in face of competing demands.

B. Equipment Needs.

Each of the following urgently needs skilled investigation to meet the needs of present-day life:-

1. Calipers, fastenings, crutches etc.- especially as regards weight, folding, expansion, flexibility, speed and convenience.
2. Wheelchairs - especially as regards weight and folding, in the age of the family car and of the mini-car. (The larger models at present in use cannot be fitted into the boot of some quite large modern cars, so creating many major financial problems.)
3. Walking frames, "chariots", tricycles and toys generally. There are numerous prototypes in use.
4. Invalid cars. Active co-operation with bodies already working on this problem is needed.
5. Aids to independent living - long-handled tools, cooking equipment, bathroom fittings etc.. Much work has been done already by various bodies, but more remains to be done if true independence is to be achieved.

Public expenditure in these fields is already at full stretch, and ASBAH must expect to add its quota to those charitable funds already being used on these and kindred matters.

C. The Welfare Needs.

1. The need for Welfare Workers has been the subject of recent discussion and approval in principle by the ASBAH Committee. One or two Branches have also moved into this field with similar appointments on a full or part-time basis. There is a need for a great expansion in this field especially in the densely populated areas, where living conditions create special problems within the affected family. There are also different but related needs in rural areas, often due to isolation, transport problems, low living-standards and the like.
2. The provision of Play Schools and Day Nurseries. This has also received some attention by a few Branches, usually in the larger cities. Lack of these facilities can and does lead to more serious problems for both the child and the family as a whole.
3. Special provision is needed for the orphaned SB & H child and this is an urgent need in certain areas around the main treatment centres. The provision of a "home" atmosphere, rather than an institution is an over-riding requirement if the orphaned and handicapped child is to have a reasonable chance in life.
4. The most pressing needs of parents are often however far less sophisticated than those implied above. They can be and are met by the simple process of meeting others facing the same day-to-day problems, including especially meeting those whose children are growing up. Every incentive must be given to encourage the growth of more local Branches and the holding of local meetings.
5. The establishment of a Benevolent Fund to meet permanent or temporary ~~needs~~ calls for help, including financial or other care for members' children who may become orphaned or in other need.
6. A vast amount of information still needs to be published in the form of leaflets or booklets, covering the complete range of problems likely to be faced by the affected family and by its medical and other advisers. A considerable expansion of LINK is also planned for the future. Requests for information about SB & H form a large proportion of the Secretaries' post.

The money for items 1 to 3 above is unlikely to be forthcoming from Public Funds in anything like sufficient quantity. Items 4 to 6 above call for considerable funds at Head Office.

D. Educational Needs.

1. Adequate publicity for the problem and its size, so that the admission of SB children into normal schools becomes the accepted (and acceptable) policy, whenever it is in the best interests of the child concerned.
2. The provision of special facilities e.g. ramps, lifts etc..
3. Encouragement of special classes for the physically-handicapped within normal schools, as already successfully in operation in some areas.
4. Provision of more Special Units and Special Schools to supplement the few now in use, and to provide facilities for the additional year's schooling.
5. Research into the best educational methods available and also into the forecast future needs year by year.
6. Active co-operation with research projects, such as those already in hand under the G.L.C. and elsewhere.

Here again it is highly unlikely that Public Funds will be available to meet our special needs. Cuts in public expenditure in the education field are already in operation, and here again if ASBAH does not find funds, no-one else is likely to do so in an adequate manner. The over-riding importance of adequate schooling was tellingly emphasised in the World in Action film.

E. Vocational Training and Employment.

Two senior members of the staff of a Special School for the Physically Handicapped have recently stressed to me that the problems of the SB school-leaver are already causing them grave concern. They emphasised that ASBAH must begin to work on this problem now if the most difficult problem that lies ahead of us is not to become insoluble in a few years' time.

1. Existing Special Training Centres are too few in number to cope with more than a fraction of the likely future number of SB school-leavers, let alone other handicaps. Unless there is a significant break-through in research into causes or treatment, the numbers involved are likely to increase.
2. Considerable work is called for in the development of new Courses to meet present-day needs - e.g. speed-writing, computer-programming, punched-card operation, printed electrical circuits etc..
3. The proximity of Centres to Non-Residential Training Centres needs careful consideration. Some degree of Aptitude Testing and forms of co-operation with Universities will no doubt be needed.

Here again competing calls are too numerous to make it likely that existing funds will do our work for us.

F. Branch Requirements.

1. The U.K.

To date money has flowed from the Branches to Head Office, and we should not have made the progress we have if this had not been the case. There is a growing need to reverse this flow of money in order to:-

- (a). Encourage the rapid growth of new Branches and the sub-division of present ones where needed.
- (b). Lead to the provision of an adequate advisory service for Branch Officers on such matters as Administration, Finance, the Medical and Welfare problems of their members and other matters.
- (c). Assist various local projects which have been or ought to be started to meet particular local needs.
- (d). Advise Branch Officers on continuous and close contact with Local Authorities, especially County and County Borough Health, Education and Welfare Departments.
- (e). Where necessary ensure that local Branch Officers are competent to cope with the work put upon them. In particular to ensure that parents of handicapped children are not burdened indefinitely with the task of administering growing Branches, so creating further problems both for the Branch and for the affected family itself. Such is the result of our present structure, and many local Secretaries find themselves seriously over-worked in their spare time.

2. Overseas.

ASBAH already has numerous contacts abroad and must never become insular in the handling of its problems.

- (a). The active encouragement of the growth of similar Associations abroad should rapidly become an important feature.
- (b). The encouragement of research work of all kinds should be supplemented by the free flow of information.
- (c). International Conferences should naturally form a part of this work at all levels, not only medical.