

## The function and operation of a parent support association

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### **Abstract**

The use of a parent support organisation and its responsibilities and limitations are described. The difference between a parent support organisation and an association of limb deficient children is discussed.

### **A parent support association**

When a child is born with a limb deficiency the parents are immediately faced with interminable questions. The obvious ones are related to the disability, but since the mother is already in direct contact with a medical team, which she may reasonably expect to be able to cope with these, medical questions are not necessarily, to her, the most pressing or bedevilling.

We 'lay-parents' are normally ill-prepared for this type of birth defect. We have been forewarned of all the major catastrophes which can occur but have never had explained to us that this form of 'minor mishap' is even possible.

Immediate concerns tend to polarise around the "why?", "why me/us?" . . . The answers and explanations are rather unsatisfactory in that "we don't know" is not easy to relate to!

Leaving the cocoon of the maternity hospital also breaks a link with the medical profession and this is when the feeling of isolation, of being the only one like this in the whole world, can become utterly overwhelming.

Now! . . . is when there must be a 'Reach'.

If a support group does nothing else it can produce very convincing evidence that there are others around who have been there! To find other families to share experiences with is a wonderful cloud dispersant!

This alone, I think, is justification for there

being a parent support group, however, I believe, our responsibility goes much deeper.

As, inevitably, we have a very wide cross-section of parents, with an almost equally diverse range of limb deficient children in our contact group, we build up a comprehensive insight into all aspects of the problems addressed and the treatments administered across the spectrum of limb deficiency. This does not mean we are becoming medically competent or that we know the correct treatment for any specific disorder. It does mean that we are well placed to provide links between families; matching those whose children are similar and putting them in touch with each other. We are also in a position to provide information about the range of medical specialists who may be useful to them.

The support and encouragement we have to offer can be given in a variety of ways.

Families can be introduced to each other on an individual basis, which may foster friendship and mean that there can be a mutual approach to the solution of problems.

The Association can co-ordinate and encourage the setting up of local branches where families can get together from time to time as a group. This may on occasion be semi-formal; a meeting with guest speakers, visits by adult amputees, health professionals, or informal; 'tea parties' or outings of various sorts.

Other links come through the formal 'administrative' structure of the Society. These are the 'benefits' of belonging to a membership organization.

The publication of a regular newsletter gives a forum for the sharing of experiences. It will be enhanced if contributions are encouraged from professionals as well as parents and, of course, the children themselves.

Note that in this activity correspondents may

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express views and relate experiences which are not necessarily those which would be supported by the parent organization. Provided this distinction is made clear, any contention so generated can only be regarded as healthy.

The other activity which is usual in 'our' sort of organization is the publication of informative fact sheets. One has to be very careful in the preparation of this type of material. It is important that we do not allow individual preferences or bias to creep in; that we inform without trying to influence.

In any discussion it will not be long before some suggestions are made that support should be given to some aspect of research. This can be a very fraught area for 'amateur' associations such as ours, and is one where advice from relevant professionals should always be sought and welcomed. It is as well to be clear at the outset that 'research' can mean different things to different people:

The first proposal which is likely to arise (at least from parents!) is for research into the causes of congenital limb deficiency. It is arguable whether this is suitable for a small parent-support organization to invest limited resources. As congenital limb deficiency is comparatively rare, and moreover has a wide variety of forms, it seems unlikely that statistical surveys will prove fruitful. Perhaps co-operation with a professional 'scientist' who is looking for causes into some specific birth-defect-type (by facilitating access to relevant members) is the more effective way forward.

There are many other subjects in the broad area of research which will be suggested. Physical characteristics and the treatment of different types of malformed limbs will interest practitioners involved in associated disciplines. When some project, either in pure research or the development of hardware, is in need of

financial support, then it behoves us, in our support group context, to seek expert guidance as to the ultimate prospective usefulness of the investigation and the likelihood of its achievement.

I think all that I have written above was said, rather more succinctly by our 'Information Officer' when she said:

"As an Association we are appreciative of the complexities of the hand and arm and the skill of those practitioners who specialise in the care and treatment of the limb.

We cannot express support for or against any individual or Centre.

Each case being individual we cannot express opinion regarding relevant or irrelevant treatments nor influence these.

We can collect data from all sources — publications, practitioners, and patients — and make available such information as is advisable to relevant persons and link like with like among our families where applicable.

Any individual expressing an opinion based on *their* experience must ensure that it is clearly understood to be a *personal statement* and is not on behalf of the Association."

My own, final, predication would be to suggest that we should be very aware of the distinction between a 'parent support group' and an 'association for children with limb deficiency'.

I am not sure 'we' always make this distinction.

After all, parents need support; children have to grow up to cope with their disability.