



## **Organisation Issues and Models for Childhood Cancer Parent Groups** **Julian Cutland (South Africa) and Simon Lala (New Zealand)**

These notes are based partly on discussions at a workshop held at the ICCCPPO Conference in Porto in September 2002, and also on the experiences of various member organisations of ICCCPPO over recent years.

### **Introduction**

Many parent groups start off as local support groups, often closely related to a specific Paediatric Oncology treatment centre. They normally develop a close working relationship with the hospital and the staff there, and have their primary focus as the support of the families who are treated at the centre. If they do fund-raising, it is normally from the local community, and is spent within the local area.

However, many groups have evolved from purely local activities to having a national presence, perhaps joining with other regional parent groups to do so, and this can sometimes be a difficult transition for groups to be made.

There are different “models” that can be adopted by parent organisations when they “go national”, and each of them has advantages and potential problems. The aim of this note is to identify these models, and the issues that may arise from them.

It is not the intention to be prescriptive as to what the “best” model should be. There are many variations between countries, in terms of the medical care provided, the social services available, and the legal framework in which parent groups operate. The combination of these makes it necessary for each group to adapt and organise itself to be best able to deliver on the objectives that it sets out to achieve. There are however some basic ideas that a group should take into consideration when they decide to formalise their existence.

This note is based on the experiences of some parent groups, and will hopefully be developed over time as other ideas are contributed by different groups.

### **Legal Framework**

One decision that each parent group must make is whether it is going to be just an informal association of people, or whether it will become a formal, legal organisation. Remaining as an informal organisation will generally imply that they are unable to raise funds from the public. Most countries will have legislation that governs the conduct of groups such as parent organisations. Typically, such organisations will be described as “welfare organisations”, “charities”, “informal organisations”, “NGOs” (non-governmental organisations), or “NPOs” (non-profit organisations). For convenience, we will use the term NPO to denote all such groups. Because NPOs will normally collect money from the public to achieve their aims, most countries have some form of regulation and registration of this sector, so that there can be the assurance that such moneys are utilised for the purposes for which they are collected.

Typically, the state will require that there is a formal constitution for the NPO, which defines its objectives, specifies how the organisation will be run, how its officers are elected, and how its finances are controlled. There is normally the requirement for the NPO to submit reports and audited accounts on an annual basis to the regulating body within the government. Issues of “governance” are often emphasised, in order to ensure that the organisation is run along proper business lines, and that there is no opportunity for the misuse of public funds.

In addition to whatever is required legally to operate as a NPO, there are often other aspects of legislation that a parent organisation can conform to. Examples of this would be getting recognition / registration in order for donors to get tax benefits on their donations (eg the USA 501[c]3 registration), or for the organisation to be able to claim back VAT or other taxes.

The important message is that parent groups who want to raise funds need to be aware of the legal framework that they have to work within, and must make sure that they conform to it. There is often a legal person among the parents who could help with this, or someone will know a lawyer who would be prepared to assist if asked.

### **Local and National organisations – different focuses**

Before we get into the potential relationships between local and national organisations, let's look at some of the different activities they tend to be involved in.

It is not intended to do more than highlight some of these activities. For more information, please refer to the excellent handbook "Your Are Not Alone", which is produced by the Candlelighters Childhood Cancer Foundation in the USA (and which is given to all new members of ICCCPO).

#### **Local groups:**

As mentioned previously, these are normally focused within a geographic area, and often on a particular treatment centre. They aim to support all of the children and families in that area, and work closely to maintain and improve the facilities of the treatment centre. Their activities may include: organising mutual support groups, and providing hands-on support for the families, children and parents; running programmes for the children, siblings and parents (including camps, outings, etc); funding medical equipment or staff posts; improving the general facilities at the hospitals (eg play rooms, etc).

Their strength comes from their close association with the area, and many are very successful in getting great community involvement, including raising funds locally. Typically they are very "hands-on", and have close contact with individual parents and families. They are able to develop or adapt the programmes that are most appropriate for their local situation and communities.

#### **National Groups:**

Many countries have national parent groups, which have evolved in a variety of ways. The main activities at a national level can include: advocacy and national policies for childhood cancer; creating relevant programmes on a national scale, and if necessary assisting local groups to implement them; providing assistance and guidance to local groups, to get established, and to be effective on an ongoing basis; fund raising for both national and maybe local projects.

They tend not to have direct contact with the individual parents, but rather focus on the bigger issues, and in helping the local groups.

One thing that parent groups unfortunately have to address in some less developed countries is the funding of treatment, where this is not adequately paid for within the public health sector. This can be at either local or national level, or both, and can end up being a major reason for the group's existence.

### **Organisation Models**

If there is just one locally based group in a country, then most of the issues covered below are not relevant. However, where there are several local groups, they will ideally evolve a way of working together for the good of all of the children and families in the country. This section describes the four main "models" for this relationship that we are aware of within different countries represented in ICCCPO.

Many of the differences have come about for historical reasons, depending on the way in which local groups were formed and evolved, and the inclinations of the parents involved.

There are many possible variations within each of the different models, but we hope that we have captured the main characteristics of each of them.

### **Model 1 – Completely independent groups**

In this model, there are several local groups who function completely independently, with little or no contact between them.

#### Advantages:

Each group retains its local character, supporters, identity and funding base, and addresses the specific local requirements.

#### Disadvantages:

The groups will obtain no benefits from addressing common problems, and they will not be able to speak with a common voice on matters of mutual interest.

### **Model 2 – Independent Groups, with a National Umbrella Body**

This model normally arises where there were pre-existing local groups who have established themselves with significant activities, and probably a funding base within their communities. They have then decided to form a national organisation where they can come together for mutual benefit, but each retains their own names and identities separate from the “umbrella body”. A typical name for such an umbrella body may be a “National Alliance” or a “Confederation” of parent organisations. ICCCPPO itself would fall into this type of model.

Individual parents belong to the local groups; it is the groups themselves that belong to the Confederation.

Much of the sharing of experiences and programmes would be on the basis of “this works for me, see if you can adapt and use it yourself”, rather than on consciously setting out to develop common programmes for everyone.

The main power will remain firmly with the local groups, who continue to have complete autonomy, subject possibly to some mutually agreed goals and standards. The national body has very limited power to enforce its views on the local groups, and it will only be successful only so long as the local groups perceive that there is value to them from belonging to it.

There could be two variants of this model:

One option would be for the umbrella body to have a distinct legal existence, and be registered as a NPO in its own right. This would allow them to do fund raising itself, in addition to what is done by the local groups.

A second one is for the body to be an informal organisation, which provides a forum for the groups to come together for mutual interest, exchange of ideas, and to decide on coherent approaches to common problems. However it would be restricted in what it would be able to do by way of fund raising.

#### Advantages:

Each local group retains its local character, supporters, identity and funding base.

However they have a basis in the Confederation where they can speak with a common voice to address mutual interests. These may include aspects of government policies, eg for Health or for Social Welfare.

It also provides a forum for the exchange of information, experiences and programmes.

It provides the opportunity to do fund raising on a national scale, and tap sources of funds (eg of country wide organisations) who may possibly not want to support purely local organisations.

#### Disadvantages:

This model has the potential for conflict between the National Alliance and local groups in areas of fund raising. Clear agreements as to which local or national groups will approach specific potential donors are desirable.

There is also the potential for conflict if the relative roles and functions of the local and national groups are not clearly agreed.

This model loses the possibility of creating a common “brand” for Childhood Cancer in the country. The public will possibly see several different organisations and names apparently doing the same thing, and hence creating some confusion in the mind of the public.

### **Model 3 – A National organisation with local groups - diffused control**

In this model, there is a national organisation and several local groups, which share a common name and identity, but where the local groups voluntarily choose to belong to the national organisation.

The local groups generally function as in the previous models, but there may be some constraints on them resulting from their membership of the national organisation. The role of the national organisation is to address some or all of the functions described above, including providing leadership and guidance to the local groups.

Typically, each of the local groups, and the national organisation, will have a separate legal identity, registration as a NPO, etc. Each could be able to do its own fund raising.

The “balance of power” between the local and national levels could vary. In some cases the national organisation could be funded by the local groups, in others it may raise its own funds for national purposes, or for distribution to member local groups. There could also be variations in the amount of control of policies, programmes, etc that the local groups can exercise over the national body, and vice versa.

Compared to Model 2, the national body will probably play a more proactive role in identifying, developing, and assisting in the implementation of, common programmes.

#### Advantages:

All of the advantages of Model 2 apply, with the addition that there is a common identity and “brand” across the whole country.

Also, there is an even greater weight for the organisation when it speaks on national and advocacy issues.

There is greater potential for the development of common core programmes, for the benefit of all groups, and a reduction of the “reinvention of wheels”.

#### Disadvantages:

Similarly to Model 2, there is the potential for conflict between the national and local groups in areas of fund raising, and with the relative roles and responsibilities at local and national levels.

Clear agreements as to the “rules of the game” for these are definitely desirable, so that the different parts of the organisation are not, and are not perceived to be, in competition for the same resources.

### **Model 4 – A National organisation with local groups – central control**

There are considerable similarities with Model 3, but in this situation there is much tighter control over the local groups from the national level. Generally, there will be one legal entity for the whole organisation, in terms of registration as a NPO, covering both the local and national components of the organisation.

Typically, local groups are formed (and disbanded) under the control and approval of the national organisation, and there are common policies and standards (eg for financial practices, programmes, etc) across all of the groups.

Some programmes and projects may be funded at a national level, from national fund raising, with other programmes and fund raising done at a local level, involving the communities in each area. Again, there can be “balance of power” issues, and there need to be clear agreements as to what the relative roles are between local and national. There needs to be an appropriate degree of autonomy for the local groups to function effectively, while conforming to key values and goals of the overall organisation.

#### Advantages:

All of the advantages of Model 3 apply.

#### Disadvantages:

Since there are probably local variations in the needs of parents and families, there is the potential that local groups are too constrained by national policies from meeting specific local requirements.

There is a danger that the organisation could become detached from the “grass roots” parent groups, and tend towards being a centralised, bureaucratic organisation.

This could be a problem especially within a large country, with many local groups, where it may become very unwieldy to try to have too tight a central control over local groups.

There is still the potential for conflict between local and national level functions.

## **Discussion and Conclusions**

As was stated earlier, there cannot be a “one size fits all” situation for how parent groups are organised within a country. Interacting aspects of history, geography and personality will all play their parts in shaping the future and defining what is possible and practical in a given place and time.

We do however firmly believe that there is great merit in having a national organisation for the childhood cancer parent organisations within each country.

We also believe that it is absolutely essential to have strong and active local groups, who are the people to provide hands-on support for the individual children and families.

The balance between these two components, and how the relationships between them are defined, is something that each country will have to work out for itself. It is highly desirable that this is done with good will on all sides, recognition of the potential benefits and dangers of the alternatives, and with a determination to see that the best is achieved for the children and families. There is then a far better chance of building something of value for the long term.

It is hoped that these notes will give some assistance to parent groups who have to decide where they go in the future, and how they want their organisation to evolve. They are based on a range of practical experiences, from people who have faced some similar decisions in the past. However they are by no means cast in stone, and we would welcome contributions from other parents and groups, who feel that they can enter into the discussions, and add something of value to other parent groups from their own experiences.