



## **"Your Group Is Not Alone"**

# **A Handbook for New Childhood Cancer Foundations, especially in Developing Countries**

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This document has been compiled by various members of the Executive Committee of the International Confederation of Childhood Cancer Parent Organisations (ICCCPO).

It incorporates ideas and experiences that have been gained over the years by those people, and is intended to be of value to all those involved in the creation and development of groups involved with childhood cancer, especially in developing countries.

It is hoped that it will evolve over time to incorporate input from many other people, so that it becomes a true reflection of the experiences of groups throughout the world.

If you would like to make any comments or suggestions as to how this document could be improved, please pass them on to the ICCCP Secretariat ([icccpo@vokk.nl](mailto:icccpo@vokk.nl)) or the editor of the document, Julian Cutland ([cutland@icon.co.za](mailto:cutland@icon.co.za)).

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## **Section 1: Setting the Scene**

### **1.1 Introduction:**

One of the guiding principles of all those involved with childhood cancer is that the patients and their families should never feel that they are alone in their difficult times. In fact the title of a leading publication by the Candlelighters Childhood Cancer Foundation in the USA was "You are not alone".

This document is intended to extend this concept, from relating to individuals coming together into groups for mutual support, to that of parent groups assisting and supporting other groups to start and to develop.

Since childhood cancer parent groups are well established in most developed countries, the particular focus of this document is on groups in developing countries, where the treatment of children with cancer is frequently sadly lacking, in both quantity and quality.

The aim of this document is to draw together ideas and experiences from groups in many countries, to provide guidelines to assist Childhood Cancer Foundations to get started, and to fulfil a really valuable function over the long term.

### **1.2 Target Readership:**

The intended readership is those people who are potentially involved in the initiation and development of groups which have the focus of supporting children with cancer and their families.

They could be involved in the activities of:

- "Starting": Are thinking about setting up childhood cancer parent groups / foundations, especially in developing countries.
- "Developing": Are involved in such a group already, but want to achieve more than they are doing.
- "Mentoring": Are involved in such a group and who want to help to start and develop other groups elsewhere in their country or region.

These people could be: parents; or doctors; or nurses; or social workers; or psychologists; or a combination of any or all of these. In fact, anyone who has an interest in children with cancer and their families.

### **1.3 Definition of a Childhood Cancer Foundation ("CCF")**

There can be a wide variety of types of groups involved with childhood cancer, from ones which are entirely run by parents, to ones which have little or no parent involvement and may be, for example, primarily for the funding of various medical activities such as treatment.

It is not the intention to be prescriptive as to what is the best model for a given situation. It will depend very much on the situation in the country or the local regions; on the involvement of public sector health services in treatment of childhood cancer; and also on the number, capability, enthusiasm, and availability, of the potential range of people who have an interest in achieving worthwhile things for children with cancer.

We do however consider it very desirable that there should be a significant parent involvement in these groups, even if they are not the primary players or drivers in the group.

We have decided to use the term "Childhood Cancer Foundation" ("CCF") in this handbook as the broad generic term to cover all of those organisations, formal and informal, which have a primary focus on the child with cancer, and which ideally have some significant level of parent involvement.

### **1.4 Abbreviations used**

Abbreviations used for convenience are:

"HICs", for High Income Countries. These are sometimes called the "developed countries".

"LICs", for Low Income Countries. These are often also referred to as "less developed countries", "developing countries", or some other descriptions.

ICCCPO: The International Confederation of Childhood Cancer Parent Organisations. See section 7.1 for more details.

WCCF: World Child Cancer Foundation. See section 7.1 for more details.

SIOP: The International Society for Paediatric Oncology. See section 7.1 for more details.

### **1.5 Why have a Childhood Cancer Foundation?**

One of the most traumatic experiences that a family can face is the diagnosis of a child with a life threatening illness. From that point onwards, their lives will never be the same again.

Parents will face many new stresses and challenges; these may be emotional, financial, spiritual, or just the practical problems of coping with the situation and continuing to lead their lives in as normal a way as possible.

Parents who have lived through this experience are in a unique position to appreciate what new parents are going through, and this has often been the motivation for the creation of parent groups, to provide mutual support for other parents and their families.

Because of the particular requirements of the treatment and (long term) follow up of childhood cancer in their countries, many groups have expanded their efforts beyond direct support to other families, and have become involved in providing a wider range of services to the families, and to those involved with the treatment and care of the children. These activities will be covered in more detail later.

In general, CCFs operate at 3 different scales or levels. These are:

- Local: the focus here is on the support for children and families, and on supporting one or more treatment centres, in a particular geographic area.
- National: the aim at this level is that of advocacy, to: raise general awareness; to ensure that government health policies recognise childhood cancer as a priority; and that these policies are implemented to provide good treatment and support for the children and families. This may be done by one national CCF, or by local groups working together in concert. At a national level, we also sometimes see one group helping to develop other groups within their country, and develop the treatment centres, to help to ensure the same treatment for all children and families across the nation.
- International: here the focus is on liaising with groups in other countries, to share experiences and knowledge, and to assist newer groups to develop their capabilities.

### **1.6 Evolution of Childhood Cancer Foundations**

The first parent organisation to be formed was the Children's Cancer Association of Japan (CCAJ), which was founded in 1968 by parents who had lost a child to cancer. This was followed by the Candlelighters Childhood Cancer Foundation in Washington DC, USA in 1970. During the 1970's and 1980's, many other parent groups were formed, primarily in the developed world.

In 1992, several of these groups met and decided to form an international association, as a forum where they could exchange ideas and experiences and learn from one another. This led to the creation in 1994 of ICCCP, the International Confederation of Childhood Cancer Parent Organisations. From modest beginnings, with just 12 members, ICCCP has grown over the years, and in 2008 has some 105 members from 65 different countries.

One major development from the late 1990's onwards has been the emergence of groups in many countries from the developing world. This has come about for various reasons, including the increasing recognition that childhood cancer is a major cause of death in these countries, and that it is possible for treatment to make a significant impact on reducing the death rate and improving the quality of life of affected children, despite all of the other problems in those countries. Even where it is not possible to make major improvements in the survival rate, palliative care for the children and support for bereaved families can become a significant focus of groups.

In spite of the very significant challenges that they face, many of these groups have begun to make a real difference in the availability and quality of treatment for children with cancer, and for the support that is available to the children and families.

### **1.7 Treatment of childhood cancer**

Childhood cancer is relatively rare; it is generally accepted that about 1 child in 600 will develop some type of cancer before the age of 16. This is obviously far less than the incidence of cancer in the adult population.

Up to the 1970's, the prognosis for children with cancer was poor, with overall survival rates of around 20%. However with improved treatment protocols, which were developed and proven over the years by means of cooperative trials covering many treatment centres (internationally and nationally), the overall survival rate in the HICs has improved to over 75%.

It has been proven over many years that the survival rates of children with cancer are far better when they are treated at specialised paediatric oncology centres, by paediatric oncologists. The same is also true for teenagers and adolescents.

It has thus become the standard in all countries that there are specialist treatment centres, which are normally part of a tertiary / academic hospital, and which are within the paediatric discipline (rather than with other oncology departments). Standards for a Paediatric Cancer Unit were defined by SIOP, and are documented in one of their guidelines [see references in Appendix A]. One of the criteria is that, in order to have the "critical mass" of patients to justify and sustain the specialist staff, there should be a minimum of 30 to 50 new patients referred to the unit per annum. One consequence of this approach is that there are relatively few treatment centres, and thus many families will need to travel from outlying areas to received treatment. This has several implications for CCFs, which will be covered later in this handbook.

It must be pointed out that, even in HICs, not every major city has a treatment centre. Ideally, each country will have a national policy for the treatment of childhood cancer, and the number, size and location of these units will be part of an overall plan to ensure optimal treatment for all children.

St Jude Hospital, in Memphis, Tennessee, USA, is one of the leading centres for childhood cancer in the world. They have been involved with the establishment of paediatric oncology treatment programmes in many countries around the world, and have defined the steps which are considered to be the best way of establishing a paediatric oncology programme in LICs. This model is given in Appendix B.

One thing that must be emphasised is that the incidence and treatment of childhood cancer is very different from that of adults. It is very rare for children to develop "life style related" cancers, such as cancer of the lungs, the skin, the bowels, etc, which can be caused by smoking, exposure to the sun, and diet, respectively. So the mix of the types of cancer is very different from that of adults.

The treatment protocols are also different. The many trials over the years have established the optimal treatment for children, in terms of drugs and dosages, which give the best results, and these are normally significantly different from those given to adults. It is by no means unknown for a child to be referred to an oncologist who deals with adults, and who starts the child on an adult protocol, often with very poor results. This is one reason why all involved with childhood cancer are very insistent that children and adolescents should be treated at a specialist paediatric cancer unit.

One document which is of relevance in setting the ultimate goals for a CCF is "Childhood Cancer - Guidelines for Standards of Treatment and Care", prepared by ICCPO and SIOP in 2002. Refer Appendix A for details.

### **1.8 Realities of childhood cancer in Low Income Countries**

There are several myths related to childhood cancer. These include:

- Children don't get cancer.
- Even if they did, it is a death sentence anyway and can't be treated.
- It is a "white man's illness", and indigenous populations don't get it.

All of these are obviously false, but we have found that these beliefs can be widely accepted as fact, sometimes even in the medical professions. It should be one of the major tasks of a CCF to address

and correct these beliefs, among the public, government, and health professionals.

It is very probable that the burden of childhood cancer is not recognised in many countries. It is believed that in South Africa (although it is one of the more developed countries on the African continent and has good childhood cancer treatment centres), less than half of the children with cancer are actually diagnosed. And of those that are, many are already in an advanced stage of the illness, with obvious implications for a poor prognosis. The situation is probably far worse in other countries in Africa and other LICs.

There are doubtless many reasons which contribute to this situation. It could be a lack of knowledge on the part of medical and nursing staff. It just may not be "on the radar screen" for many of them, especially in rural areas. The symptoms may be interpreted as being caused by many other diseases, often until the cancer is very far advanced. [There is some discussion later on regarding the use of a set of Warning Signs for Childhood Cancer, which are intended to raise awareness in the primary health sector; also see Appendix C].

It has to be recognised that the treatment of cancer is generally expensive, and requires significant medical resources. Where a country is faced with limited budgets for their health systems, it is understandable that childhood cancer is fairly low down on the priority list. This is exacerbated where the country is faced by the burdens of infectious diseases, such as malaria, TB, cholera, and HIV/AIDS. In these situations, it may be a rational and cost effective decision to allocate medical resources to those areas and illnesses which have a higher "payback" in terms of the number of children's lives saved per dollar spent.

So in LICs, childhood cancer has to compete for scarce medical resources with many other demands, which may be considered to have a higher priority. However this should not be a reason for inaction; there is much that can be done to improve the situation of children and their families, even in such constrained circumstances. It is possible to make a real difference.

### **1.9 You are unique**

It has to be recognised that no two CCFs will be exactly the same, and do the same things, even in the same country.

Each country has it's own unique set of conditions, and there will be differences in:

- medical, hospital and treatment facilities;
- social welfare system and support;
- culture;
- health system priorities;
- socio-economic and education levels;
- geography and transport system; etc.

So what one CCF does may be quite different from another. It will depend on their local and national situations, and the priorities that the group identifies as the most important things for them to address.

BUT: there are many aspects that may be similar, since many problems faced in childhood cancer are common across all countries.

What we have tried to do in this document is to draw together some of the ideas and experiences from many countries, especially in the less developed countries. The aim is to provide some guidelines which will assist CCFs to get started, and to fulfil a really valuable function over the long term, making a significant difference to the lives of children with cancer, and their families.

It is hoped that this document will be a starting point, and that in time it will incorporate additional contributions based on the experiences of people in many other countries, who have faced the challenges of childhood cancer and have come up with better ways to tackle them.

## **Section 2: Getting started**

### **2.1 Who might start a CCF**

The first CCFs to be established were usually started by parents of children with cancer, and had the main aim of providing mutual support between the families. This model, of the organisations being largely comprised of, and led by, parents, is the most common one in the HICs.

However we have seen that, in many countries and especially in LICs, it is not just the parents who have taken the lead in establishing the groups. It can in fact be anyone who provides the initial impetus. This might be a doctor, a nurse, parents, social workers, volunteers, etc, or any combination of them.

Quite often it has been just one person who has had the initial idea and enthusiasm, and who starts the ball rolling. They then begin to talk to other people (eg doctors, parents, nurses, the community), and find that there are many others who are willing to join in and assist.

The main requirements for getting a group going are:

- enthusiasm, because this is infectious, and makes people believe that good things are possible;
- long term commitment, because it really does take a long time and a lot of effort to make things happen;
- the time available to get things done;
- and the vision to see how things might be made better.

### **2.2 It is a team effort**

One of the most important things to recognise right from the start is that: **YOU CANNOT DO IT ALONE**. But it can often happen that just one person can provide the catalyst to get things going, and then other people become inspired to join in as well.

The treatment of a child with cancer requires a multi-disciplinary team, comprising the doctors (including paediatric oncologists, surgeons, radiologists), nurses, social workers, psychologists, and many others. Allied to, and an integral part of, this team must be the parents of the children.

As a consequence of this, building a successful CCF requires the close working together of all of the people who are involved.

SIOP published one of their guidelines in 1998 on what they called the "Therapeutic Alliance", which they saw as being essential and which brings together all of the medical and related disciplines, together with the parents. [See references in Appendix A].

One of the more "interesting challenges" facing a CCF can be to bring these different players together to work for a common cause. It is critical to have an involvement and "buy-in" from all parties if there is to be real success.

### **2.3 Know the current situation**

It is not enough just to have good intentions. If one wants to persuade people (and especially those with money), you need some facts to back you up.

So one will need to do some research, and document the results. Ideally you should know most of the following:

- The numbers of childhood cancer cases known in the area / region / country;
- An estimate of how many there should be (an overall incidence rate which is often used is about 12 cases per year for each 100,000 children under the age of 15);
- How many are treated at which hospitals;
- What success rate do the hospitals have. It may be difficult to establish this, or get it from the doctors. It is a question that can cause bad relationships with doctors, so it may be advisable to start without bothering them for such statistics.
- It is also important to know the local cut off age for paediatric admissions. There may be the need to establish relationships with adult services as well, so as to identify children and young people who are being treated in adult wards. This can be a lot of extra work with regards to relationship building, especially given the number of areas of medical speciality that take adult

cancer patients, but is well worth it to pick up on families who can feel quite lost or alienated in the adult systems.

- What contacts / relationships do the hospitals have with other childhood cancer-related organisations (eg SIOP; St Jude; other childhood cancer centres; other CCFs);
- What medical and support staff are available in the hospitals. Note that social workers can be good links, as they often work on community/hospital interface so have many useful networks and contacts.
- What other facilities are available in or related to the hospitals, eg schools; space; playrooms; lodging facilities.
- What resources are available, from the state, hospital, or other organisations.
- What other local organisations (eg NGOs, Foundations) are there which do, or could, provide some of the support that is required.
- Are there any other organisations supporting childhood cancer in the: region; country; or neighbouring countries. It will be desirable to develop relationships and to share things with them.

It is important to recognise that one doesn't want to reinvent the wheel, or duplicate what exists already.

#### **2.4 Getting yourselves known**

One thing that you need to do is to get yourselves known, and to build some credibility. There are many simple and practical ways in which this can be done. For example:

- Visits to hospitalised children. Remember to first get the OK from the medical staff and hospital authorities before you do this.
- Birthday parties, special meals, or entertainment for the children, particularly for special occasions such as Christmas or religious days).
- Taking the children on trips out of the hospital (for a meal out, or to the cinema, etc), if their blood counts allow it. Remember that parental and medical consent is probably needed for this.
- Simple additions to the facilities in the hospital, such as toys and games for the kids, perhaps TVs, or providing chairs or settees for use by the parents.

Often it is very easy to get donations in kind (ie in goods or services, rather than as money) from people and companies, as long as you can identify the need and explain why it would be so useful.

It can be very valuable to use the media effectively. They are often keen to have "human interest" stories, so invite them to attend or send them pictures of events. However you should be clear what message you are wanting to send out.

This will all start to get your organisation known, and will attract interest from the community.

## **Section 3: Getting off the ground**

### **3.1 Getting the core group together**

As we said earlier, it has to be a team effort, and one of the first things to be done is to get the core members of the team together. This should include medical professionals; hospital staff, including nurses; parents; and other willing volunteers with relevant skills.

It is really important to identify at least one key health professional, who will act as champion and support for the establishment of the group. This is important in terms of gaining credibility with other health professionals, establishing lines of communication to inform other parents about the group, and gaining access to the hospital when volunteers eventually start with visits etc. But if one cannot find the right professional at the beginning, don't give up.

It has to be recognised that some doctors are not happy or comfortable with parent involvement, and feel threatened or challenged by "empowered parents", who may (in the doctors view) ask too many awkward questions. This is an aspect that many groups have faced at times, but it is something that working together for a common cause can overcome. The SIOP Psychosocial Guidelines (see references in Appendix 1) can be useful in showing that it is the accepted best practice worldwide for there to be a "therapeutic alliance" of all the people involved, including parents.

Many doctors, because they are employed within the medical system, are constrained in what they can do to challenge the status quo. Making too many waves can sometimes be career limiting! However a CCF, which operates outside of the formal medical structure, can often be a catalyst for improving things. Much can be achieved by asking the right questions, and being seen to have the interests of not only the children and their families foremost in their minds, but also those of concerned medical professionals.

Things will probably initially start off with an informal group, but may develop a more structured identity as time goes by.

The important thing is to start to work together as a team, involving all the stakeholders in the decisions that are made, and the work that is done. There should be a buy-in from all the people involved that what is planned is worth doing, and will make a difference.

One thing to do early on is to agree the basic "rules of the game" as to how things will function within the group, and who will be responsible for the different aspects. These will include such things as:

- Parents don't give medical advice;
- There must be mutual respect between all the parties;
- Confidentiality with regard to patient information must be respected;
- Who can / should talk with the media;
- What facts are distributed into the public domain;
- Managing the institutional relations;
- Identify health professionals with whom the group can discuss any issues that may arise.

### **3.2 Identifying the priorities**

There will always be more things that one would like to do than there are resources to achieve them. This is especially true in LICs, where resources (eg money, people, skills, time) may be very limited, and the challenges can sometimes seem insurmountable.

Groups will always be in the situation where priorities must be agreed upon, and realistic targets set for what they wish to achieve in the short, medium and long term.

One recognises that some goals will require much more time and effort before the end results become evident. Persuading the government that it needs to have a policy for childhood cancer, or getting a house in place to accommodate parents from out of town, may take years to achieve. However the rewards when these goals are eventually achieved are enormous.

It is necessary to set long-term plans but, for the group to earn credibility, short term goals that show quick tangible benefits and results are also extremely important.

To be able to decide on these priorities, a group needs to:

- document all of the things that they would like to do;
- establish what resources will be needed to achieve them, and the likely success of each;
- realistically assess what resources (funds, people, etc) you have, or can generate;
- describe the benefits and value that will be achieved if you are successful. These may be a mixture of "hard" values (in monetary terms), or "soft" values, in terms of improved quality of life for the children.
- decide where best to allocate your efforts and resources among all the things that you would like to do.
- build up a portfolio of the things that the group wants to achieve, and decide which ones give the best "return on effort".

Further down the line, groups will probably develop more formal business plans, and these are covered in more details in section 6.3.

Deciding on your priorities is not a once-off exercise; it is something that should be done on a regular basis, as needs change, as objectives are achieved, and as the group's capabilities and resources evolve.

As mentioned previously, it is recommended that, especially early on, there are some "quick and easy" things in the portfolio, which can show rapid success and help to make the group visible and get it known. Often these can be done with little money, by mobilising effort of the community, and getting donations in kind.

### **3.3 Getting to know the families**

It is important to get to know the parents, children, siblings, and survivors, and to understand their real needs (emotional, practical, etc). They are the ultimate "consumers" of what you will be doing. You should also become known to them, so you can represent their needs in the things that you do and say.

There are many ways to meet the parents and families. For example, it could be done one-on-one; you can invite several families to chat over coffee; you can arrange talks for the parents; or you can gather some of the children together in the playroom.

### **3.4 Information for the families**

There is a lot of information available which is suitable for parents and families, either from the web or from other childhood cancer organisations. However much of it is in English, or other European languages, and it is normally targeted at people with levels of education and understanding accepted as normal in HICs. Thus it is not necessarily suitable for people with limited ability in those languages, or who have only a basic level of education.

It is often a priority of CCFs, to take, adapt, and translate material from elsewhere, to make it appropriate and in terms understandable to the majority of parents locally. Most other organisations involved in childhood cancer will be very willing to make their material available.

A newsletter can also be a good way of making information available, and getting yourselves known. Please remember that the group should get the sign-off from the doctors for any "medical" information (eg about the illnesses) that you put into your brochures, booklets, etc.

There is more about providing information in section 4.1.

### **3.5 Other organisations and groups**

Where to get assistance is dealt with in more detail in section 7, but it is worthwhile to mention here the importance of identifying the various groups with whom you should be in contact.

In section 2.3 we mentioned that you should identify other organisations working in the area of childhood cancer. These might be in other centres in the country, or in your region, and you should build alliances with them to make sure that you work together and don't duplicate efforts. There

may be one or more of these groups which could act as a "mentor", and give you the benefits of their experience.

It may also be possible to enter into a twinning relationship with groups in other countries; see section 7.3.

It is also important to identify any other organisations which might be able to assist you in what you want to do, to ensure that there is an understanding of common ground between you, and to aim to cooperate with them. There is so much to do that you don't want to have unnecessary fights with other groups, nor to duplicate activities.

One type of organisation which it is well worthwhile to cultivate are the service clubs, such as Rotary, Round Table, Lions, Kiwanis, etc. Many groups have received great support from these clubs, both from them sponsoring specific projects, and from the contacts and advice that their members are able to provide. It should be high on a CCF's priority list, to enlist their support for the projects which have been identified.

### **3.6 Activities in the hospital**

Since the hospital is where the children and parents will be spending much of their time during treatment, groups should aim to have a programme of regular activities there.

It is recommended that you have a group of volunteers (including parents), who are trained in how to talk with other families and patients, and who visit the hospital wards. Volunteer programmes are discussed in more detail in section 6.6.

It is essential that groups have the permission from the hospital for planned activities to take place. Initially this may be from the doctors rather than from the hospital authorities. Groups need be aware of the sensitivities that may be involved, and should be sure not to make any enemies in the process.

It can be useful if these activities can be done in conjunction with the social workers or a similar type of person, who can also provide training as well as opportunities for group and individual debriefings following the activities.

### **3.7 The importance of statistics**

It is vital that there are good statistics on childhood cancer available. Ideally these will be captured and managed through a good registry, and one good source of expertise and software for cancer registries is IARC, the International Association of Cancer Registries, based in Lyons, France. [More details in section 7].

Often, the responsibility for a cancer registry is handled by the state or the medical profession; it should not matter who runs it, so long as it is done well, and the relevant statistics are available when required. It is not the function of a CCF to run the registry, but rather to act as a catalyst and support to ensure that it is done well and professionally.

It should be a population-based registry, capturing information such as the age, sex and geographic origin of the child, as well as the diagnosis and stage of the illness.

Statistics are necessary to be able to know how many children are in your area of the nation are diagnosed, with what types of cancer, and from which regions. This is essential information when justifying the number, capacity and location of treatment centres which may be required. From this, it should also be possible to estimate how many children are probably not being diagnosed.

Such statistics are also necessary to be able to measure the success of initiatives. For example:

- If there is a programme to try to improve the numbers of children who are diagnosed, then groups will want to be able to measure the increase in numbers of new cases, by region, to be able to determine how effective the programme has been.
- Similarly, to determine whether there has been a significant improvement in the stage of the illness at diagnosis, ie the children are being diagnosed earlier than before.
- And if you have a programme to encourage patient compliance with the treatment protocols (eg by providing funds for transport to ensure that the family can bring the child back for

treatment), then you want to be able to measure any improvements in the rate of non-compliance or abandonment of treatment.

Having reliable statistics will add credibility to any proposals which are made, and enable one to justify the continuation, or otherwise, of the programmes which are run.

## **Section 4: Typical Programmes of CCFs.**

This section is intended to give brief descriptions of some of the wide range of programmes that have been initiated and run by CCFs in different parts of the world. It is by no means a definitive list, but rather to give an indication of the many different things that groups do get involved in.

### **4.1 Parent and Child Support**

Childhood Cancer affects not just the child, but also the whole family.

For the child, it means several years of coping with treatment such as chemotherapy, radiation and maybe surgery, with their often unpleasant side effects.

For the parents, it can mean major changes to their lifestyles, and many additional stresses on them. Apart from the emotional upheaval caused by the diagnosis, there are many practical and financial issues that they will need to deal with over a period of probably several years.

For the siblings of the sick child, it can seem as if they are forgotten, and all of the family's attention is focused on the ill child. For grandparents, other relatives, and friends, they wonder what they can do to help their loved ones through this period.

One of the primary aims of most groups is to help to support the whole family through what will be one of the most difficult and traumatic periods of their lives. Some of the ways in which might be done are outlined below.

Some studies have shown that survival rates in LICs have been increased by supporting the families' needs, with particular benefits in reducing the abandonment of treatment.

#### **Support and Sharing**

**Support groups:** For new patients and families, a friendly face who understands what they are going through can help to make them feel less alone in the new hospital environment. Other activities can involve: organising of discussion / lecture meetings for parents; helping parents to meet other parents (and survivors); or even just a meal or a walk together.

**Social Workers:** The psychosocial support for the children and their families is recognised as one aspect that can make a great difference to the family, in helping them to cope with the many stresses that they encounter once their child has been diagnosed with cancer. Social workers can play a key role in providing this support, and groups may feel the need to fund people in this sort of work, depending on the level of support that is available through the hospital or social services.

**Bereavement support:** The period of bereavement can be an especially trying time for families. It is possible to provide moral and sometimes material support for families before, during and after bereavement, by means of specially trained counsellors. One can also organise annual bereavement services, as well as meetings of bereaved parents, siblings etc.

**Survivors groups:** Long-term survivors can face many challenges, and having groups for mutual support can be of value.

**Recreational support:** Organising for the children to go on outings, parties, etc can provide a welcome break from the constraints of the time the children have to spend in hospital. Several countries have camps especially for children with cancer, and their siblings, and they may sometimes be able to accommodate children from LICs.

#### **Information and Education**

**Information provision:** Parents and children are faced with a whole new world, with specialised medical terminology, large hospitals, and many new things to learn that affect their child. You can provide Information Packs and books for parents, with a combination of: local information about the hospital and the surrounding area; medical information about the illnesses and the drugs used; and psychosocial and practical information, on how to cope with the many new stresses and challenges faced. You can also have a library of books, articles, etc for the

parents, and produce informative newsletters. Some of the booklets produced by parent organisations are specifically for children.

Although there is much information available on the web, please be very careful with it. What you can get from reputable sites (such as the ones listed in section 7.2) is fine, but there is a great deal of harmful material on some other sites. Please make sure that you check it all out with the medical specialists before you pass it on to the families.

Web Site: You can create your own web site, as a means of communicating with families, and also with donors and the general public.

Educational liaison: The continuity of school life can be an ongoing anchor in a sick child's life. This programme would provide material for schools where children have been diagnosed, and people to talk to them if required, so that the school understand the situation and the child can return to school with minimum problems.

Educational support: Some long term survivors are educationally disadvantaged because of the loss of school time during treatment. Some support for a child's secondary or tertiary education is one way of ensuring that the survivors are able to fulfil their academic potential. There are also a number of school projects which can be adapted to suit your own needs, such as E-learning, etc.

### Practical Support

Practical items: For some of the children, wigs, wheelchairs, and medical devices such as catheters or prostheses, can really improve their lives. For those families who lack the money to provide adequate nutrition for their sick child, food parcels might be provided.

Transport Funds: When a child from a remote area is referred to one of the specialised treatment centres, the family have even more of a disruption to their lives. Added to all of the other issues, they have to find the money to bring the child long distances back to the hospital for ongoing treatment. Sometimes this can present major problems, especially to those families from a disadvantaged background, and a CCF may provide funding for transport to ensure that a child is not prevented from completing its treatment due to financial constraints on the family. Some groups have found that this is one very successful way to minimise the abandonment of treatment by families.

Accommodation for parents: With the children being treated at the specialist centres in major cities, many families need to travel long distances from home for treatment, and often stay there for extended periods. This obviously adds to the financial burdens on the families. To assist them, many groups provide a "home away from home" to give the parents a place to stay when the child attends the hospital for treatment. In HICs there are other organisations which provide this service (the best known being the Ronald Macdonald Houses), but in many countries these do not exist and the CCF has to provide this sort of accommodation. These houses can also be valuable places to be in contact with the parents, and to learn about their needs.

Parent Respite: Some groups are able to arrange accommodation etc for parents and families to have a break away from their homes, which gives them a chance to relax and to lead a more "normal" life for a short period.

### **4.2 Support for Treatment Centres**

The children (and their parents) will spend long periods during treatment and hospitalisation in the specialist centres for childhood cancer, which are in the main tertiary hospitals. Many hospitals are forbidding place, especially for children, and there is often the opportunity to make the environment in these units as "child friendly" a place as possible.

Basic decorations and furnishings: such as paint, curtains, duvets, etc

TVs, games, toys, play room: To make the children's lives more stimulating and interesting during their visits.

Parent facilities: Provision of lounges, laundry, kitchen, chairs, etc in the hospital for parents. This can make the lives of the parents less stressful, if they are able to maintain some of their normal parenting functions in hospital.

Volunteer programme in hospitals: It can be of great value to have dedicated volunteers who work and play with the children in the wards. CCFs typically may provide the materials used, plus other costs of volunteers, including specialised training of the volunteers.

Support staff in wards: Some CCFs employ staff to assist in the treatment centres, such as a toy bank supervisor, play therapist, "ward mother". The aim is to make the time in hospital of the children and their parents less traumatic and stressful, and to ease some of the load on the medical and nursing staff.

Medical / Hospital Equipment: Although the hospitals should in theory provide all of the medical equipment and facilities required for the treatment, in practice, for budgetary reasons, this is often not the case in many institutions. Sometimes it proves necessary to provide important equipment and facilities to supplement that provided by the hospital. This might include items such as: volume infusion pumps (used for giving chemotherapy to the children at a very controlled rate); monitors; drip stands; beds; and other equipment.

Support for Medical Staff: Being part of the public sector hospitals, medical and nursing staff often have limited access to funds to attend conferences and meetings, or purchase books and journals, etc. Some CCFs provide support or scholarships to assist them in this area.

Funding for staff posts: The specialist treatment centres are often under-resourced, and the childhood cancer units are regarded as one of the most emotionally stressful places for a doctor or nurse to work. Some CCFs aim to provide funding to supplement the existing staff. This could potentially cover the range of staff in the units, including: doctors; nurses; social workers / psychologists; and the support staff for clerical, data capture or research work. This might also include staff who run the childhood cancer registry.

Palliative care: Some CCFs, especially in countries where there is not adequate treatment, have felt the need to provide a palliative care service, to ensure that, even though a child may not be able to be cured, they can at least die free of pain and with support and counselling for the families. It can also be desirable in other countries, especially where there is not a clear policy for palliative care, or where there is limited or no access to the appropriate drugs.

### **4.3 Support for Treatment**

This can be a contentious area.

Some CCFs take the view that the funding for treatment is the responsibility of the government and/or the medical aids / insurers. They believe that if they do any funding of this nature, they will let the medical authorities abdicate some of their responsibilities and open up a bottomless pit for themselves, into which they would have to pour large amounts of funds.

In other countries, for example where the medical attention may be free but there are limited funds for the drugs for treatment, CCFs might in fact pay for some of the medicines used for treatment, and this can be a major portion of their expenditure. [For a cost-effective source of drugs, see the details of the IDA foundation in Chapter 7].

Even where they do provide funding for some aspects of treatment, the CCFs should also be advocating for the health authorities to be responsible for the full treatment of the children, covering both the medical staff and the drugs required.

It can be a difficult call to make, and depends very much on the circumstances in each country.

### **4.4 Advocacy and Public Awareness**

There are many areas in which CCFs may get involved, to create awareness with the public, and to

advocate for the children and families. These can include:

- Raising awareness, in both the government and the society in general, that children do in fact get cancer, and that it is curable.
- Sometimes advocacy can be effective at an individual level, to assist a specific family to receive the treatment that it should, and possibly in disputes with medical aids or health insurance organisations.
- Lobbying with the government to ensure that there is an effective and implemented policy, ideally at a national level, to ensure good treatment for all of the children with cancer.
- Where there is a government policy which should ensure the treatment of the children, but it is not being implemented effectively, then this can be an area for the CCF to become involved, to ensure that the health authorities meet their stated obligations.
- Lobbying to ensure that there is full integration of the child back into school and into society, without any form of discrimination.
- Publicising the Warning Signs for Childhood Cancer, via various media and government channels, with the aim of improving the number of children diagnosed, and to get the diagnosis made at an earlier stage of the illness. See Appendix C for more details.

## **Section 5: Getting Formalised.**

### **5.1 A major step - getting formalised**

Much can be done with an informal organisation, with little or no money but with lots of enthusiasm, commitment, and effort. New CCFs probably don't want to get into formalising a constitution, raising money, etc, too early; this can divert effort and resources away from achieving useful results quickly.

Sometimes it is possible to work under the wing of another established organisation, and so avoid or postpone the time for setting oneself up as a separate charity.

However a time will probably come when needs are identified which will require significant amounts of money, which will have to be raised from the public. At that stage, the CCF will need to formalise itself, and become a registered charitable organisation.

Each country will have its own laws governing charities and non-profit or non-governmental organisations (NPOs / NGOs), and the CCF must comply with all of those. In some cases there are well-defined criteria for how the organisation must be set up, how it needs to be controlled, how governance issues are managed, etc. All of this is to ensure that the funds raised from public sources are well-managed and are actually used for the purposes for which they are raised.

You will normally need:

- To identify what your objectives are; this is usually a necessary part of the constitution.
- A constitution: one can involve friendly lawyers, and maybe other NPOs, to assist with writing this.
- To register as an NPO / charity; this is normally a requirement before you can raise money from the public.
- A bank account.
- An office, with computers, e-mail, etc (which could initially be in someone's home).
- A formally elected committee and officer bearers, who will be responsible for the organisation, its activities, and its funds.

### **5.2 What sort of organisation?**

There are various models which have been identified as being used by various parent groups around the world; refer to the paper on the ICCCPPO web site (Cutland & Lala 2002 - see Appendix A) for further information.

There are two areas which will require some in-depth thought and discussion. These are who will control the organisation, and whether it will be a local or national body.

#### **Control:**

Many CCFs, especially in the HICs, were started by parents, and they have ongoing control by parents built into their constitution. There may be representatives of the medical profession on the Board, who often function mainly in an advisory capacity. These CCFs will often employ professional staff to run the organisation, but have a parent-controlled Board that decides on policy, direction, and the things that the CCF wishes to do.

There are positives and negatives to this approach. On the one hand, because the parents have themselves been through the experience of having a child diagnosed with cancer, they have an intimate understanding of the issues that new parents face, and are very likely to ensure that the focus of the organisation remains on doing what is required to support the children and their families.

On the other hand, because the parents are essentially a random selection of the population, they do not necessarily have all of the skills and experience which are required to manage a large and successful CCF, and their control could hamper progress. This is sometimes the situation in HICs, but it is especially likely to be true in LICs, where there may be only a few parents with relevant skills, expertise and free time who join the CCF, and who are able play a leading role in the organisation.

This situation is often made more difficult because the parents will generally serve on the Board in a voluntary capacity, and so will not necessarily have the time available to do all of the work required, particularly if they have to hold down full time jobs as well.

In contrast to such "parent controlled" CCFs, others may be much more like conventional charities, in that the leadership, management and control will reside with people with a mixture of backgrounds and experiences. Some may be doctors, some parents, some from other areas which are involved in childhood cancer, and some may be there as volunteers because they believe in the cause. The members of the Board will be there because of the expertise and experience they bring to the organisation, and the ongoing day-to-day management of the organisation will be handled by professional staff, with the range of relevant skills.

There is no easy solution to this, as much will depend on the specific people who are available and willing to take leading roles, and with the enthusiasm and commitment to make things work. Whatever the situation, it must be reemphasised that the focus of the organisation must be on the support of the child and the family, and that it is necessary to harness the contributions of all people involved towards the common goals, whether they are parents, employed staff, volunteers, or any of the team responsible for the treatment of the children.

One cautionary point that we would make is that new CCFs should be conscious of the possibility that they may become little more than a vehicle for funding the aspirations and ambitions of one or more medical doctors. There should be sufficient checks and balances built into the constitution, and through the choice of members of the Board, for the organisation to avoid being "hijacked" in this way.

#### Local or national?

Many CCFs start off in one location, often with very close links to a specific treatment centre. This is usually OK, since it does lead to a very tight focus to the activities of the organisation. However in due course it may well transpire that, especially if the treatment programme in the country develops along the lines of the St Jude model (Appendix B), that other treatment centres will be opened in the country. This may well lead to the formation of other CCFs, each linked to the different treatment centres, with the potential for fragmentation of the efforts.

We believe that in any country, one does ideally need to have a single identified organisation that can talk to the national government, and to the public in general, on behalf of all of the children with cancer in that country. This must not distract from the need to have local groups in the appropriate geographical areas, to provide close hands-on support for the children and the treatment centres. The national organisation could be an "umbrella" body with loose links to several autonomous CCFs. Or there could be just one organisation, with subsidiary geographical groups, operating with one identity and governance structure.

There is no simple answer, but it is something that people should be aware of and address when there is the need to do so. What is important is that all groups involved with childhood cancer work together, and share their knowledge and expertise, for the common cause.

## **Section 6: Developing and Running the Organisation.**

This section is concerned with various areas which CCFs will face at some time, and which may not necessarily be immediately obvious when the organisation starts up.

### **6.1 The importance of good governance**

It is vital that your organisation has very good governance in place. Without it, the long-term existence of the organisation and its credibility can be at risk.

It is your good name and reputation which will bring in funds and support for the long term.

It takes a long time to build up credibility, and it can take just one unfortunate event to destroy the work of many years.

To use an extreme example, if it was reported in the press that the organisation had purchased a luxury car for the chairman's wife, most of your funding would probably disappear overnight.

So, like any reputable business, one must have all of the checks, balances and procedures in place, to ensure that, among many other things:

- all of the funds donated to the organisation are properly accounted for;
- the money is only used to meet the objectives of the organisation, and all expenditure is fully accounted for;
- that there is a clear process for the approval for expenditure, with limits defined as to who is allowed to approve different levels of expense;
- that the accounts are audited on a regular basis, preferably by a well known and reputable firm, and they are available to anyone who wants to see them;
- that all agreements are reviewed by a legal expert; this can often be arranged on a pro bono basis;
- that the organisation always does things that are completely legal and ethical.

It may be necessary or desirable to bring onto the Board people with specific skills, such as financial, legal, and general business expertise.

One important thing to remember is that credibility will come from being seen to deliver on promises, and that donors must know that their support is being used for what it was intended.

### **6.2 Define your "ethos"**

All organisations will go through changes over the years, and new members will step forward to take leadership roles. It is important that the organisation agrees clear rules as to what it will and won't do, which will define the ethos of the organisation.

Some possible examples of this could be:

- be very clear about why you are doing what you do;
- the benefit of the children and the families are the primary focus of all that the organisation does;
- don't receive money from the government if it limits your ability to advocate for what you want to achieve;
- similarly, don't accept money from any other organisation (such as a cancer society) if it limits your ability to advocate for what you want to achieve;
- don't accept donations or initiate projects which you cannot maintain and sustain;
- be clear who from whom will and won't accept donations (eg tobacco companies);
- don't provide services which are a state obligation (eg treatment, medical staff salaries, etc);
- don't rely on a single or very few donors;
- have a target for administration costs as a percent of your total expenditure (eg 10%).

### **6.3 Developing the business plans and project plans**

Normally, before any person, company or trust will contribute to the organisation, they need to know what the money or goods will be used for. So, once one gets to the stage of handling significant amounts of funds, it is necessary to have a clearly documented business plan for the organisation.

This will spell out: what activities you plan to carry out; why they are necessary; what they will achieve; and what resources are needed to make them happen.

It is normal for the plans to be broken up into separate projects. To put it very briefly, a project:

- is a set of activities carried out to achieve a number of clearly stated objectives, which should be measurable (so that you know they have been completed);
- has a start and end date;
- the project plan identifies:
  - o what you want to do;
  - o what benefits it will create - ie why you think it is important;
  - o how you will do it;
  - o what resources are needed (money, equipment, & people);
  - o when it will be completed;

A programme has many of the attributes of a project, but is ongoing over time, ie has no completion date. But it must also have measurable objectives / deliverables.

When it comes to raising funds, it is normally very useful to have a specific project or programme which a donor can fund, and "put their name on".

#### **6.4 Fund raising**

There is a very good paper on fund raising by Joanna Ramos on the ICCCPPO web site; see the references in Appendix A. This section has some simple basic thoughts on the topic.

Many people feel that "I could never go and ask people for money". However one can get over this by taking the view that:

- I am not asking for myself, it is for the children and their families.
- Don't think of it as asking for charity. Remember that people want to feel good about themselves. You are actually doing them a favour by giving them the opportunity to achieve this, by helping sick children and their families.

It is a well-known saying that "people give to people"; the personal contact and credibility is vital.

Fund raising can be easy if you have a "good product", and the passion to get the message across.

One must have a "saleable product" that you want people to buy into; this can be a small or large project, or an ongoing programme. So having good business and project plans are critical.

Donations in kind can be very valuable; eg a shop can donate food, or toys, rather than money.

Marketing, branding, and public relations are all related things that you will have to consider at some times. [See the paper on marketing and branding by David Stones (Appendix A)]. You may be able to get what you need in these areas on a pro bono basis.

#### **6.5 Communications**

Good communication is essential with all of the many stakeholders the organisation is involved with.

These include:

- the parents and patients. They are the reason you exist, and they need to know what is happening.
- the medical staff and the hospitals. These are your essential partners in all that you do.
- the donors and supporters. Hopefully they will provide the means that you need to achieve your objectives. They need to be kept informed about your activities, and acknowledged for their support.
- the government, and especially the health department. They have the responsibility for treating the children, and setting the policy and the budgets for health care.
- the general public and the community.
- the media, who can assist by giving you the visibility that you need to achieve things.

There are many ways of communicating effectively, and the message and the medium must be appropriate for the target audience. There can be a mixture of: brochures; newsletters and other publications; press releases; face-to-face meetings; articles in newspapers and magazines; and interviews on TV and radio. It can be very valuable to have good contacts within the media, to get the visibility and publicity one wants.

## **6.6 Managing volunteers**

Volunteers can play a critical and essential role in helping the organisation function. There are two broad categories of volunteers that you will want.

Firstly, there are those people who will visit the children and families in the hospital. It is essential that you have a formal process for the selection, training and support of these people. See the papers by Barb Smeltzer and Sadie Cutland on this topic (Appendix A).

And you will also want to harness other volunteers who will assist with the range of activities in running the organisation. They could bring skills in some relevant area (such as financial, legal, fund raising, PR, marketing, etc), or they may be available to assist with admin tasks or at events and functions.

## **6.7 Continuity and transition**

All organisations will go through periods of growth and change, in both structure and in the people involved. The aim should be that these changes do not cause disruptions to the organisation; this can be achieved by thinking and planning ahead, and developing successors, to ensure continuity and a smooth transition. There are some useful thoughts on this topic in the paper on "Continuity and Transition" on the web site (Appendix A).

## **6.8 Know what you have achieved**

People like to see the results of their efforts, or the outcome of donations they have made. So make sure that you keep a record of what you have done. In coming years, you will be able to look back with satisfaction on all the things that have been achieved.

It will also help with getting support in the future if you can show a good track record of actually achieving results and delivering on promises.

There should be photos taken of the "before and after" situations if, for example, you do a renovation of the wards.

The statistics should be kept, of the numbers of children diagnosed and treated, and the success rates achieved, so that one is able to show the some tangible impact on the survival of the children.

## **Section 7: Where to get assistance.**

### **7.1 Valuable organisations**

There are several international organisations with a major focus on childhood cancer, which are listed below. In addition, there are many national organisations, and the details of these can be found on one or more of these web sites.

ICCCPO: The International Confederation of Childhood Cancer Parent Organisations.  
([www.icccpo.org](http://www.icccpo.org))

This is the organisation which brings together parent organisations from around the world, with the aim of sharing expertise and experiences between all of the groups. Their web site contains all of the previous newsletters and articles, which should be of value to CCFs, as well as information on meetings and conferences, and contact details for all of the member organisations. There are also links to many worthwhile web sites related to childhood cancer, which are a very rich source of information.

ICCCPO has an annual conference, normally held in conjunction with the SIOP conference, as well as regional and continental meetings for parent associations.

WCCF: World Child Cancer Foundation. ([www.worldccf.org](http://www.worldccf.org))

WCCF was founded by ICCCP in 2007, in order to have a vehicle to raise and distribute funds to develop the treatment and support of childhood cancer in developing countries. It is hoped to have generated sufficient funds to be able to support the first projects by 2009.

SIOP: The International Society for Paediatric Oncology. ([www.siop.nl](http://www.siop.nl))

SIOP is the main international society for the doctors involved in paediatric oncology, and has members in most countries in the world. They organise an annual conference, which is held in different countries around the world, and are involved in the coordination of various trials to improve the treatment of the children.

There is a SIOP Nurses group, which organises some of the sessions at the conferences.

They also have continental groups, who typically organise conferences every two years.

There is a committee which focuses on Paediatric Oncology in Developing Countries (PODC), and which is also instrumental in organising and running research to identify more cost effective treatments in those countries.

St Jude Children's Research Hospital ([www.stjude.org](http://www.stjude.org))

St Jude is one of the leading hospitals in the world specialising in childhood cancer. They have been at the forefront of research and improvements in the treatment of the illnesses for many years.

They have an outreach programme, where they partner with hospitals in other countries to help to build the capability and expertise there.

St Jude has a website ([www.cure4kids.org](http://www.cure4kids.org)) which is focused on providing support and advice for doctors in other countries, and it also has a distance learning programme for nurses.

IARC: The International Association of Cancer Registries. ([www.iarc.fr](http://www.iarc.fr))

Based in Lyons, France, IARC is the source of cancer registries used by many countries around the world. They provide both the software for the databases, and the advice and expertise to set them up and run them.

IDA Foundation ([www.idafoundation.org](http://www.idafoundation.org))

IDA Foundation is an independent not-for-profit organization, established in 1972 in Amsterdam by a group of pharmacists committed to contribute towards greater accessibility of healthcare supplies in developing countries. IDA's core objective has remained to provide high quality essential drugs and medical supplies at the lowest possible price to the not-for-profit healthcare sector in developing

countries.

IDA Foundation is the world's largest not-for-profit provider of pharmaceuticals and medical supplies, offering a wide range of quality assured products from stock.

More information

IDA Foundation. P.O. Box 37098. 1030 AB Amsterdam. The Netherlands

### **7.2 Web sites and other information**

Rather than repeat the list here, the ICCCPo web site contains links to several sites which have been proven to contain valuable and reliable information on childhood cancer.

The URL for the page is: [www.icccpo.org/links.html](http://www.icccpo.org/links.html)

### **7.3 Twinning programmes**

Twinning programmes have been in existence for 10 to 15 years, and typically bring together a treatment centre in a HIC with one in a LIC. There is usually training provided at the HIC centre for the LIC medical staff, with ongoing support and advice, and possibly the provision of medical supplies as well.

Recently, there has been twinning initiated between CCFs in HICs and in LICs, which may sometimes happen in conjunction with a twinning programme on the medical side. This support can take various forms, from advice and encouragement, to funding. The aim is to assist the CCF in the LIC to develop increased capability and to build its capacity to deliver programmes of value to the children and their families.

It is hoped that this sort of programme will become increasingly common in future years.

## Section 8: Concluding remarks.

There are some general points which are worthwhile reiterating here:

- One must recognise that creating and running a group to serve children with cancer and their families is a long-term venture; you must be in it for the long haul.
- It is often just a few people who get things started, and who by their enthusiasm and vision can get others motivated to become involved.
- One can often get some "quick wins" but many results will only be achieved over several years.
- One can always do something to improve the situation for the children with cancer and their families.
- One may never get to the ideal solution, but one can make a real difference, and give hope for the future.
- Always remember that it is for the benefit of the children with cancer and the families, now and into the future.

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It is hoped that the readers of this document have found it of value.

It didn't set out to provide all of the answers, but rather some guidelines which will enable people involved in CCFs, especially in their formative stages, to learn from the experiences of people who have been through it in various countries, and maybe to avoid some of the mistakes which others have made.

As was said early on, each organisation will be unique, in terms of: the environment it has to work in; the challenges which confront it; and the ways in which it faces up to and overcomes those challenges. But we hope that some of the ideas here will better equip people in CCFs to be successful in what they set out to achieve.

It is hoped that there will never be a "final version" of this document. If it is to be really successful, it will in coming years also incorporate more ideas and experiences from many more people who have been through the experiences of setting up and running Childhood Cancer Foundations in developing countries.

If you have anything which you would like to contribute to future versions, or suggestions as to what you would like to see included, please pass them on to the ICCCP O Secretariat (see details on the contact page of the ICCCP O web site).

Also, if you feel that you have any policies or procedures which could provide useful guidelines to other organisations, please offer them to be shared through ICCCP O.

Your comments on whether you found the document of value would be appreciated. In particular:

- were there aspects which you disagree with?
- are there areas which you felt should have been there, but which were omitted?
- are there areas which you think should be expanded?
- are there some things which you think are redundant?

Have your say, and help to make it a more useful document!

And to conclude with a commercial:

If your group is not already a member of ICCCP O, please consider joining it. The relevant forms are on the web site, along with some comments on the benefits which membership brings.

Even if you don't consider that you are a "parent organisation", so long as you have a major interest in childhood cancer, we still would value your membership. There are many existing member organisations which have been started by, and are run by, non-parents, and they perform invaluable functions in their communities.

Belonging to ICCCP O is one way in which you can both benefit from the experiences of other groups, as well as contributing your own expertise to the common good.

## Appendix A: References and further reading

This is not intended to be a comprehensive list of all articles of interest, but rather a selection of those ones which are referred to in the main text as being relevant to particular aspects. All of this material, and much more, is available on the ICCCPPO web site ([www.icccppo.org](http://www.icccppo.org)).

### SIOP Psychosocial Guidelines

These are documents published by the SIOP Working Committee on Psychosocial Issues in Paediatric Oncology. The URL for the menu for these is: [www.icccppo.org/articles/psychosocial](http://www.icccppo.org/articles/psychosocial)

Title	Date
Charter for children in hospital	
Recommendations for the organisation of a paediatric cancer unit.	1993
1) Aims and recommendations for psychosocial care	1993
2) Guidelines for School/Education	1995
3) Guidelines for Care of Long-Term Survivors	1996
4) Guidelines for the communication of the diagnosis	1997
5) Guidelines for a Therapeutic Alliance between Families and Staff:	1998
6) Guidelines for assistance to terminally ill children with cancer	1999
7) Guidelines for Assistance to Siblings of Children with Cancer	1999
8) Guidelines for the Recognition, Prevention, and Remediation of Burnout in Health Care Professionals Participating in the Care of Children with Cancer	2000
9) Refusal, Non-Compliance, and Abandonment of Treatment in Children and Adolescents with Cancer	2002
10) Valid Informed Consent and Participative Decision Making in Children with Cancer and their parents	2003
11) Non-Conventional Therapies in Childhood Cancer: Guidelines for Distinguishing Non-harmful from Harmful Therapies.	2004
12) Communicating with the Dying Child	2005

### Other articles referred to in the text.

The page to get to the menus for these articles is [www.icccppo.org/articles](http://www.icccppo.org/articles).

Title	Authors	Date
"You Are Not Alone" - Candlelighters USA	Chesler et al	
Childhood Cancer - Guidelines for Standards of Treatment and Care	ICCCPO & SIOP	2002
Organisation Issues and Models for Childhood Cancer Parent Groups	Julian Cutland & Simon Lala	2002
Organising a Volunteer Programme in the Paediatric Haematology Oncology Unit at the Johannesburg Hospital, South Africa	Sadie Cutland	2003
Fundraising for Your Group in Developing Countries	Joanna Ramos	2005
Marketing and Branding your Organisation	David Stones	2005
Volunteer Development Programme	Barb Smeltzer	2005
Priority Setting, Benchmarking and Evaluation	Mike Mackay	2005
Continuity, Transition and Governance in Parent Groups	Julian Cutland et al	2006
A Guide for Non-Profit Organizations on Proposal Writing	Ellen Green	2006

Grant Writing - Valuable Tips For Grant Seekers	Val Figliuzzi	2006
Lobbying: Talking with Government and other agencies	Jim Barclay	2007

**Links to web sites.**

Most CCFs have their own web sites, and the ones for member organisations of ICCCPPO can be found on the "members" page of the ICCCPPO web site.

There are some excellent sites with reliable information about childhood cancer; these are referred to on the 'links" page of the web site.

**Appendix B: St Jude model:**  
**Steps to Implementation of a National Paediatric Programme in Low-Income Countries**

<b>Phase</b>	<b>Purpose</b>	<b>Requirements</b>	<b>Role of Outsiders</b>
Pilot Project	A successful pilot project demonstrates that childhood cancer can be cured in a local setting	A dedicated leader and a twinning relationship with a centre of excellence in a resource-rich country.	Complete technical and financial support.
Paediatric cancer unit	Centralises resources devoted to the treatment of childhood cancer to improve efficiency and the quality of care.	Cooperation of a variety of paediatric specialists and support of the hospital administration.	Major technical and financial support.
Centre of excellence	Development of the paediatric cancer unit into a centre of excellence.	Mobilisation of patients, parents, the government, and non-governmental organisations.	Modest technical and financial support.
Satellite centres	Extend the benefits to a wider geographical area and reduce the burden of travel on families from distant areas.	Training and supervision of satellite-centre personnel by centre of excellence with increased governmental support.	Modest technical and financial support.
Regional programme	Increased quality of care and independence of centres of excellence and satellite centres with coverage of a wide geographic area (province, state, or adjacent small countries).	The regional government takes responsibility for treatment of all children with cancer as a regional priority.	Minor technical and financial support.
National programme	Nationwide network of centres of excellence and satellite centres. National paediatric oncology association for protocol design, continuing education, and advocacy areas.	The national government takes responsibility for treatment of all children with cancer as a national priority.	Advisory only

## Appendix C: Warning Signs for Childhood Cancer

Prepared by the South African Children's Cancer Study Group  
and sponsored by CHOC Childhood Cancer Foundation South Africa

In less developed countries, very few children receive effective treatment for Childhood Cancer. One major reason for this is that many nurses (and even doctors), especially in primary health care clinics in rural areas, are not aware of the possibility that children may get cancer, and do not recognise the possible symptoms.

Also, if the disease is diagnosed at all, it is frequently at such a late stage and advanced illness as to make the prognosis for successful treatment very poor.

In an attempt to improve this situation, the South African Children's Cancer Study Group, which includes all of the specialist paediatric oncologists in the country, prepared a set of Warning Signs for Childhood Cancer.

The "St Siluan Warning Signs" have been accepted by SIOP for use in all developing countries.

### **"SAINT SILUAN" WARNING SIGNS FOR CANCER IN CHILDREN**

(For guardians and primary health care providers in a developing country)

<b>S</b>	<u>Seek</u>	Medical help early for <b><u>persistent</u></b> symptoms
<b>I</b>	<u>Eye</u>	White spot in the eye, new squint, blindness, bulging eyeball
<b>L</b>	<u>Lump</u>	Abdomen and pelvis, head and neck, limbs, testes, glands
<b>U</b>	<u>Unexplained</u>	Prolonged fever over 2 weeks, loss of weight, pallor, fatigue, easy bruising or bleeding
<b>A</b>	<u>Aching</u>	Bones, joints, back, and easy fractures
<b>N</b>	<u>Neurological Signs</u>	Change or deterioration in walk, balance, or speech, regression of milestones, headache for more than two weeks with or without vomiting, enlarging head

Some notes:

- The list of the warning signs emphasises that persistent symptoms, which do not get better within 7-10 days with conventional therapy, should be referred for further investigations to specialist centres.
- Especially, patients with eye changes like "white spot" in the pupil of the one or both eyes, or "swelling" of the eyes that do not get better with eye drops, should be referred.
- Masses (lumps) anywhere on the body, that do not get better with ointment or antibiotics, should be investigated.
- Bleeding, pallor (anaemia), bruises that are unexplained should be treated with caution, and the patients should be referred for management as soon as possible.
- Children who have persistent bone, joint and back pains cannot be ignored.
- Any new abnormal neurological findings need urgent attention. Brain tumours are one of the more common malignancies of childhood.
- Children with haematological malignancies like leukaemia can have the above-mentioned "Unexplained" and "Aching" symptoms.
- A full blood count can often indicate suspicions of leukaemia, especially if there are abnormal cells (blasts) seen on the blood smear. Patients with blasts in peripheral blood should be referred immediately to a cancer centre.