

International Confederation of Childhood Cancer Parent Organizations Parent Organisations: Partners in the Care for Children with Cancer

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The experience of a child undergoing cancer treatment can be traumatic, distressing and isolating for parents and siblings as well as the patient. The impact on the whole family has been well understood by health professionals for many years, as have the medical needs of the child, but also the necessity to provide services which look after the emotional and social needs of the family of the child. Parent support groups have been formed over the past 30 years to provide information and practical, emotional and financial support for families to enable them to cope with the difficulties associated with lengthy treatment – often many miles from home.

The Childhood Cancer International (CCI) is an international network representing organisations of parents of children with cancer worldwide. Since its founding in 1994, CCI has increased its membership in 2006 from the initial 9 members to 148 member organisations representing parents and children from 81 countries. CCI works closely with other childhood cancer organisations, in particular with the International Society of Paediatric Oncology (SIOP).

CCI's vision is to be recognised world-wide as the body representing families of children with cancer. CCI wants to see a world where the issues faced by children with cancer and their families, both in the short and long-term, are understood by families, healthcare professionals and the wider community to ensure that children receive the best possible care wherever they are in the world at the time of diagnosis and beyond.

CCI's mission is to share information and experiences in order to improve access to the best possible treatment & care

for children with cancer everywhere in the world. It does this through an international network of parent support groups and survivor networks with the common goal of providing a voice for the needs of children with cancer and their families and advocating for increased awareness of childhood cancer at both a local and international level. By working in partnership with other child cancer organisations, the need for psycho-social care for the children and their families and the long term issues faced by survivors will be promoted.

CCI's objectives are:

- Education – of parents, survivors, doctors, nurses, psychologists, teachers, etc. Parent organisations can share their special experiential expertise in order to increase each others' knowledge and to help direct services more appropriately.
- Public awareness – of the general public with regard to childhood cancer, the needs of children with cancer and their families, the increased chances of cure, and the continuing need for medical and psychosocial monitoring and support.
- Development – of parent organisations where they not yet exist. This can be at a local and national level. CCI supports and trains parents to create and lead parent organisations and so strengthen this worldwide movement. Parent organisations are encouraged to act as advocates for their children regarding medical and psychosocial care, school and education, insurances etc.
- Advocacy – for adequate medical and psychosocial care, for advance of the cure rates of children with cancer throughout the world and for equal access to insurances and employment of survivors.

In practice, the needs of families and their children differ immensely in the various countries. In the industrialized countries effectively all children get diagnosed and treated. Treatment is provided to similar standards, with more than 70 % of children surviving. Parent organisations can focus

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on psychosocial care – welfare, education, emotional and long-term survivor support.

In lower income countries, most children do not get diagnosed and even if they do, treatment is inadequate or – in the best cases – palliative. Eighty percent of children with cancer in the world fall into this category. Parent organisations in these countries are striving to educate doctors and families about early diagnosis, giving support to help families travel to a centre, and providing the drugs that are essential for treatment.

CCI helps parent organisations develop against this varied background of needs.

CCI Activities to Help Parent Organisations Worldwide to Achieve Their Mission

Information and Sharing

Annual conference – Each year CCI holds an international conference, usually at the occasion as the annual SIOP conference. This enables parent organisations, survivor organisations, support organisations and professionals to meet and take part in lectures, workshops and to informally network.

Regional conferences – CCI also organizes a regional conference wherever the continental SIOP's have their biannual meeting. These meetings provide an excellent forum to discuss the needs of children with cancer and their families a certain part of the world and to tailor informational sessions and workshops to the wishes of parent organisations and health care professionals in that specific region, to share best practices and thus try to jointly find the best strategy. Next to these joint meetings with the medical professionals, CCI organizes other regional conferences in areas where for instance a common culture or language guarantees the best communication.

These conferences also provide a forum for members to meet and share information, experiences and knowledge with other members so that all can benefit from best practise and new ideas including information on, for example:

- How to lobby governments and advocate on behalf of children with cancer
- How to create an awareness of childhood cancer regionally
- Development of parent mentoring and assistance programmes
- Developing and growing parent support groups
- Forming a therapeutic alliance with the medical team on improving conditions and services in the ward

Information – CCI provides a range of information through a number of channels. The CCI E-Newsletter is

published monthly and the CCI website is a major resource for parent organisations, and individual parents, throughout the world. It brings together information about parent organisations around the world, contains guidelines for treatment and care and manuals for setting up and running parent organisations and provides links to sites with information of value for parents and their families.

Public Awareness

International Childhood Cancer Day – This annual event on 15th February helps CCI member organisations to raise awareness and funds for use at a local level.

Development

Twinning – There are many examples of parent organisations twinning to provide development support. For example, a resource-rich member providing support to a resource-poor member, or a member with a long experience of an issue supporting another, to avoid “re-inventing the wheel”. Often these twinning programmes are jointly run with hospitals in the two different countries.

Local visits – CCI officers visit local parent organisations, often in combination with regional conferences.

Advocacy

CCI is a powerful advocate for the issues and effects of childhood cancer at an international level including long-term impact on survivors – medically, financially and socially and access to treatment and medication, if not for cure than at least for palliation.

CCI works with SIOP in developing guidelines for professionals and parent organisations to help provide holistic treatment and care.

CCI sits at the table with specialists and reviews ethical and informational aspects of innovative treatment studies.

ICCPO believes that every child deserves the chance to live and therefore helps to improve diagnosis and access to treatment in resource-poor countries. Therefore CCI set up World Child Cancer through which CCI operates to improve childhood cancer care in low and middle income countries.

CCI strives to improve support for survivors and their families to avoid these families being disadvantaged as a result of cancer.

With ever competing demands on governments, it falls to those affected, and those working in this field to advocate the

case for children with cancer. No one is better placed than those who have experienced the trauma of life-threatening illness to a child, or who have had to endure inequality as a result of it.

Local Parent Organisations and Their Activities

Local parent organisations are often linked to a certain treatment centre. Their activities differ according to the needs of parents in different places, and the resources available to them, but in general organisations work in the following areas.

They provide parents with **information** about the disease and the treatment, about psychosocial issues and coping strategies, and about the hospital and the treatment team. They also give information about financial and insurance issues. They do this through arranging presentations, discussion groups, newsletters, brochures, books, resource lists and a website.

Parent organisations provide **financial assistance**, home-from-homes, respite care, and information about practical issues such as home care, school programmes, funeral arrangements. They raise funds to help pay for treatment or to improve the children's ward in the hospital. This kind of practical support is especially seen in less wealthy countries where basic medical treatment and funds to travel to the hospital are lacking.

Most parent organisations offer **social support** through recreational programmes for children, like day trips or camps. Often siblings are involved, and sometimes the entire family. They sometimes fund computer links between ill children and their schoolmates to reduce social isolation.

Parent organisations offer **emotional support** in the form of peer-to-peer counselling. Parents who went through the same are only half a word away. There can be special sessions for mothers and fathers separately, for teenage patients or siblings, and for bereaved parents.

Parent organisations often work with the medical team to improve medical and psychosocial care and create change that will benefit them and their children. This advocacy role has increased over the last decade and today parent organisations are often involved in the design of clinical trials and the improvement or care models in their countries.

National Parent Organisations and Their Activities

National parent organisations generally coordinate and share information and resources among various local groups via meetings, conferences, newsletters and electronic media. They sometimes support local parent organisations by offering a training programme for current and future leaders and volunteers. Often national organisations provide services that would be difficult and costly to organise at each local site, like books, a national newsletter, camps. Many national organisations sponsor an annual conference for all parents or for group representatives.

National organisations often have access to health care policy-makers. They have the ear of national cancer societies and governmental bodies concerned with cancer policy, health benefits, special educational programmes for sick children, funding of childhood cancer research and treatment, etc. They act as advocates, represent parent and survivor concerns and work with national paediatric oncology organisations, nurses, social workers and psychologists. Some are active lobbyists in the legislative arena and with employers and insurance companies.

The size of national organisations varies considerably. They count between 5 and 200 local chapters; some only have one chapter, e.g., the national organisation. They also vary in their annual budget: organisations in many nations, especially those in the less affluent countries, have very minimal funds.