



What do parent groups/organizations do...and how do they do it?

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At the local level,

in specific communities and often linked to specific treatment centers, effective parent groups generate programs that respond to the five major stresses or challenges that children and parents of children with cancer face (Chesler & Eldridge, 2000): informational, practical, social, emotional and existential. As long as children get cancer parents will try to find the resources to aid their children and themselves; in so doing many parents reach out to one another and find, join or create local groups. Group activities differ according to the needs of parents in different locales, and the resources available to them, but in general groups focus on meeting some or all of the five stresses.

In responding to the informational stresses of childhood cancer groups provide parents with information about the disease and its treatments, about psychosocial issues and coping strategies, and about the medical center and staff (e.g., where to find the cafeteria, who to talk with about billing). They also help point families toward available resources in the community, especially with regard to gathering information about financial and insurance issues. They accomplish this through arranging staff presentations, parent panels, discussion groups, newsletters, special guidebooks or handbooks, and family resource libraries.

Group programs directed to the practical stresses try to ease parents' burdens of everyday living, including child-care and financial responsibilities. This is done through financial assistance, lodging for parents who must travel long distances (e.g., Ronald MacDonald Houses), respite care, and information about practical issues such as school programs or funeral arrangements and how to manage at-home chemotherapy. Many groups raise funds to help pay for treatment, purchase wigs, prostheses or in-hospital television service for children and to help pay for travel, parking or extraordinary bills for families. Some groups contribute funds to their local hospital – to improve services for families or to support research programs. These practical issues are especially potent in the less wealthy localities and nations, where basic medical treatment (trained expertise, chemotherapy drugs), post-treatment access to clean water and air, and even funds for travel to clinics are either unavailable or prohibitively expensive for all but the very affluent.

In responding to the social or interpersonal stresses of childhood cancer local groups often support parents who feel isolated and awkward with their prior families and friends and provide them with alternative social networks. They do this through group meetings and discussions, connections with veteran parents who know what they are going through, social and recreational events for the entire family, and home or hospital visits. Some groups also have established summer camping programs for children with cancer, their siblings, and on occasion their entire families. The funding and creation of telephone trees among parents and computer links between hospitalized children and their schoolmates are other examples of efforts to reduce social isolation.

Groups also help people deal with the emotional stress and personal trauma of a child's life-threatening illness, with potentially intense familial conflict and confusion, and with the ups and downs of hope and fear attendant upon treatment. Such programs focus on peer affirmation and co-counseling, "emotional rap" sessions, mutual empathy and sharing of deeply held feelings. Some groups hold special sessions for mothers and fathers separately, for teenage patients or siblings, and for bereaved parents.

In responding to the existential or spiritual stress of this illness groups help people “make sense” of their experience and place it within a framework of belief in a spiritual or secular faith, including issues of religious belief and challenge. They do this through the creation of “narrative communities” wherein parents discuss their experiences and struggles with God and Fate, where they “make sense/meaning” of their past and future situations.

In responding to all these stresses or challenges, and through all these activities, parent groups often work with local medical systems/personnel and community agencies in attempts to assert child and family needs, improve medical/psychosocial/societal care and create change that will benefit them and their children. Above all, the stresses posed by childhood cancer are potentially disempowering; the (re)development of a competent and active sense of oneself, and mobilization of collective energy and engagement with others through such group activities in one way or another help children and their families develop a more empowered outlook.

Local parent groups come in many different sizes and shapes. Some are quite large (30-50 active members and several hundred on a mailing list) while others are small (4-6 members). Some create a very formal structure, with by-laws, elected officers and a not-for-profit tax exemption or charitable license (this is especially necessary for those groups that raise substantial funds) while others are quite informal and emphasize personal conversations. Some are long-lasting (in existence for 20 or more years); others vanish in 2-3 years as leaders burn-out or as their children pass beyond this crisis (via either death or cure); still others may lie fallow for a while and rise again when newly energized parents recreate a lay support system. Some groups are run by medical staff members (these are not parent self-help groups although they may be quite useful) while others are governed by parents themselves, perhaps in coalition or collaboration with professionals. Problems of access, transportation and networking make it more likely that medical or cancer association staff members play these key roles in less wealthy areas and nations.

At the national level:

parent organizations may serve both individual parents/families and local groups. They generally coordinate and share information and resources (sometimes including money but usually information, advice and support for leaders) among various local groups via meetings, conferences, newsletters and electronic media. The United States' Candlelighters Childhood Cancer Foundation also operates an information hotline for patient/family concerns, an ombudsperson system for second opinions on medical and legal matters, and a leadership training program for current and future leaders of local parent groups. In many other countries national level organizations provide local groups with services that would be difficult and costly to duplicate at each local site (e.g., funds for group activities or to support individual families' needs, a national newsletter for parents or young people, camps for patients or survivors or siblings, and resources for group leaders). And many national organizations of childhood cancer parent groups sponsor yearly meetings, either of all parents or of group representatives.

In addition, national groups often have access to influential health care policy-makers and the ear of national cancer associations and governmental bodies concerned with cancer policy, health benefits, special educational programs for hospitalized or homebound children, funding of childhood cancer research and treatment, environmental regulations that impact cancer, psychosocially sensitive treatment protocols, etc. They often are advocates of change in the delivery of medical and psychosocial care and represent parent concerns and establish liaison with national organizations of oncologic physicians, nurses, social workers and psychologists. Some engage directly in lobbying efforts, both in the legislative arena and with employers and insurance companies, to challenge patterns of discrimination.

There is substantial variety in how and when groups are organized nationally. Of the 31 national childhood cancer parent organizations currently represented in ICCCP, 9 were founded prior to 1985 (8 of these 9 are in wealthy nations, while 7 of the 10 founded after 1995 are in the less wealthy nations). Some were initiated by parents, some by health care professionals, and some by professionals and activist parents working together. All these organizations have national Boards of trustees or overseers, ranging in size from 4-18, and in most cases the national Boards are numerically dominated (50% or more) by parents, with some professional medical

staff members, some long-term survivors of childhood cancer, and some members of the general public (e.g. public representatives or major donors).

The size of these national organizations also varies considerably. The United States parents' organization counts some 300 local groups in its family, Canada 45 and Germany 50; but the Japanese organization has 11 local chapters, Sweden 7, and The Republic of South Africa 6. The smallest nations (e.g., Netherlands, Iceland, Israel) often have only 1 group. Similarly, they vary greatly in the amount of funds they raise: associations in many nations, especially those in the less affluent countries, have very minimal funds at best.

These national organizations vary much less in the ways they raise funds and the uses to which they put these funds. A few receive a subsidy from their national governments or cancer associations, but almost all raise funds from public donations and corporate or governmental grants. Several solicit membership fees from parents/families and friends and several others require local groups to contribute to the national organization. Almost every national organization maintains an office and many have at least one paid staff member on site. Funds are expended for educational programs (aimed at the general public, parents of children with cancer, medical and social service staffs), newsletters and meetings that link parents on a personal and/or regional/national basis, support for medical research and facilities and staff, services to families and children in terms of financial assistance or special housing and travel, and development of local groups.

In some national organizations there are strong lines of accountability between local groups and the national organization. This is true in Canada, Germany and Sweden. On the other hand, in the U.S. there are only informal linkages among local groups and between local groups and the national organization, with the latter operating primarily as an information agency or educational clearinghouse and network of semi-autonomous grassroots groups. The latter form is also common in the less wealthy nations and in nations where a true national organization has not yet emerged. Part of the difference in national-local forms may be related to the history of parent organizing efforts, and the extent to which national organizations emerged from preexisting local groups (bottom-up) or established themselves first and set out to create local groups (top-down). In addition to issues of origins and tightness-looseness, the difference between power primarily being located at the national level or the local level means that some national organizations' fortunes rise and fall with the economic and political progress and commitment (or lack thereof) of strong locals. Under these circumstances some local groups have more influence on national programs and operations than do others.

At the international level:

a relatively new organization, the International Confederation of Childhood Cancer Parent Organizations (ICCCPO), was formed in the mid-1990s. ICCCPPO now includes 54 member organizations concerned with childhood cancer representing 43 different countries; 31 of these organizations are national parent groups (others are local groups not yet nationally organized or are organizations not run by parents – Associate Members of ICCCPPO). ICCCPPO has several core goals: (1) Education - of parents, educators, physicians, nurses, etc. Parents and parent organizational leaders have areas of special experiential expertise that, when shared, can increase others' knowledge and help direct services more appropriately. (2) Public awareness - of the general public with regard to childhood cancer, children's and families' needs, the increased likelihood of survival and normality, and the continuing need for medical and psychosocial checkups and support. (3) Mobilization and development - of parents and parent groups at the local and national levels. ICCCPPO seeks to prepare and train parents to create and lead parent groups and so strengthen this worldwide movement. In addition, parents are encouraged to act as advocates for their children with regard to medical and psychosocial services. (4) Advocacy - of adequate medical and psychosocial treatment, of action against social stigmatization and discrimination, and for advance in medical and psychosocial cure rates throughout the world (especially in the less wealthy nations).

ICCCPO implements this agenda through representation and liaison to national and international cancer associations, physician organizations and health agencies (e.g., World Health Organization, International Society of Pediatric Oncologists, European School of

Oncology, Monza International School of Pediatric Hematology Oncology), through newsletters and pamphlets distributed to national parent organizations, through visits to member organizations and meetings at which member organizations share their experiences and suggestions, and through a variety of special projects. One of these special projects promotes "twinning" relationships, wherein parent representatives in wealthier nations create personal exchange, training and resource sharing, and ongoing linkages with parent organizations in less wealthy nations

The member organizations of ICCCPPO share more than a common interest in the struggle with childhood cancer; they also conduct fairly similar programs, encounter generally similar organizational problems, draw heavily on personal and voluntary energy, and are deeply committed to each others' growth and ability to serve children with cancer and their families.