

## Message from the World Health Organization

In September 2011, Heads of State and Government committed themselves to integrating noncommunicable diseases – including cancers – into health-planning processes and the national development agenda of each country. They also agreed to promote increased access to cancer screening programmes.

The hardship endured by children with cancers is often concealed – and thus perpetuated – by the statistical averages on which health and development programmes and decisions about resource allocation are based. Fortunately, cancers in children constitutes a small percentage of all cancers. However, the most frequent childhood cancers, such as lymphomas and leukemias, are highly curable if detected early and proper diagnostic and treatment procedures are made available. The majority of children with potentially curable cancers can get cured even in low-resource settings, and all children with advanced cancer can benefit from pain relief and palliative care. Children's rights cannot be fulfilled and protected unless preventing and treating cancers is included as a priority within national cancer control programmes.

Today, several low- and middle-income countries, despite facing numerous economic and social challenges, are able to demonstrate success in the implementation of well-organized programmes. This is due to result-based collaborative efforts between governments, civil society, academia and research centres aimed at supporting the provision of services for the prevention, treatment and care, including palliative care, of cancers.

Together with NGOs such as ICCCPO, WHO is strongly committed to supporting national efforts to control childhood cancers in low- and middle-income countries and to reach all children in need, wherever they are excluded and left behind. If we overcome the barriers that have kept these children from the services that they need and that are theirs by right, then more will grow up healthy and realize their full potential.

Dr Oleg Chestnov  
Assistant Director-General

## About ICCCPO

The International Confederation of Childhood Cancer Parent Organizations (ICCCPO) is a global, parent driven organization that works in partnership with international organizations, governments, policy makers, civil society organizations, health and medical professionals to raise awareness and create support for childhood cancer initiatives. It also makes the case for prioritizing childhood cancer and making it an integral part of the global and national health and development policy agenda. ICCCPO builds and enhances the capacity of parent organizations, particularly in low and middle income countries.

## Member Countries

It is a network of organizations currently representing 147 parent organizations in 81 countries. Essentially ICCCPO is a family of engaged, passionate, caring individuals and professional organizations to whom childhood cancer is personally important.

Argentina	Czech republic	Iceland	Malawi	Peru	Switzerland
Armenia	Denmark	India	Malaysia	Philippines	Syria
Australia	Dominican republic	Indonesia	Mexico	Portugal	Tonga
Austria	Ecuador	Iran	Morocco	Romania	Trinidad & tobago
Azerbaijan	Egypt	Iraq	Mozambique	Russia	(west indies)
Bangladesh	El salvador	Ireland	Nepal	Senegal	Turkey
Bolivia	Ethiopia	Israel	Netherlands	Serbia	Uganda
Bosnia hercegovina	Finland	Italy	New zealand	Sierra leone	Ukraine
Brazil	France	Japan	Nicaragua	Singapore	United kingdom
Canada	Germany	Kenya	Nigeria	Slovenia	United states
Chile	Ghana	Lebanon	Norway	South africa	Venezuela
China	Greece	Lithuania	Palestine	South korea	Vietnam
Colombia	Guatemala	Luxembourg	Pakistan	Spain	Zimbabwe
Croatia	Hungary	Macedonia	Paraguay	Sweden	

# Vision

Every Child with Cancer Deserves a Chance



THE INTERNATIONAL CONFEDERATION OF  
CHILDHOOD CANCER PARENT ORGANIZATIONS



www.icccpo.org

# Every Child with Cancer Deserves a Chance

Most childhood cancers are curable if diagnosed at an early stage and provided adequate and appropriate treatment. However, while 80 percent of the affected children in developed countries survive, only around 20 percent of affected children will be successfully treated in most developing countries. To redress this inequity, worldwide ICCCPO members are committed to ensuring that every child with cancer receives the best possible treatment and care wherever they are in the world.

## 1. Key Challenges

Early and accurate diagnosis is a primary goal in childhood cancer management. It leads to increased survival, improved prognosis and minimal side effects or late effects of treatment. Sadly children and adolescents with cancer, especially in low and middle income countries, are often misdiagnosed or diagnosed at advanced stages, because the symptoms are often overlooked or not recognized. In addition, referral systems for confirmatory diagnosis and treatment may be absent or inadequate. Medical staff may not be properly orientated about childhood cancer.

### What ICCCPO has done

Some initiatives of ICCCPO and members to increase awareness and early diagnosis:

- Launched International Childhood Cancer Day (ICCD) since 2002 on 15th February to spread the message that childhood cancer is curable, if diagnosed early and given prompt treatment and appropriate care.
- Developed and distributed materials to help break myths and misconceptions about childhood cancer as well as to minimize stigma and discrimination.
- Developed and/or translated posters on early warning signs and distributed these to health practitioners, community volunteer workers and the public. Trained community volunteer health workers.
- Integrated childhood cancer messages and stories in popular TV shows and social media.
- Formed linkages and helped establish referral systems with private providers or out of state/country providers in areas where public sector diagnostic and treatment centers are not available.
- Developed and globally distributed an animated video Paultjie and the Dragon (the dragon being cancer) so as to create an understanding of childhood cancer among children. (Holland)
- Manufactured and used soft toys in shape of cows to symbolize a family of a child with cancer as part of an awareness campaign. (South Africa)
- Informed and engaged traditional healers in assisting with the early diagnosis of childhood cancer. (Cameroon)
- Conducted a mini-conference on childhood cancer for the general public and medical students. (Mozambique)
- Collaborated with the Public Health Hospitals in supporting the development of the Distant Communication Project for referrals. (Argentina)

### Way Forward

ICCCPO will scale up collaboration with governments, civil society organizations, WHO country and regional offices and other local and international partners to enhance the ability of medical professionals and health workers to recognize early signs of childhood cancer to make an accurate and early diagnosis and establish or strengthen appropriate or context specific referral systems.

## 2. Key Challenges

Expanding sustainable access to safe, affordable, effective essential medicines is one of the keys to increased survival and improved outcomes in childhood cancer. However, across low and middle income countries, access to essential medicines is often limited by :

- Unaffordable prices
- Chronic poverty
- Mistrust of generic drugs
- Shortage or unavailability of drugs
- No or low social health insurance
- Counterfeit branded drugs

### What ICCCPO has done

Some actions which ICCCPO and members did to face these challenges:

- Africa and Asia, source and supply all or some of the drugs required for treatment.
- Mexico and Colombia, initiated multi-stakeholder campaigns which led to government funded health insurance coverage for childhood cancer.
- Peru raised alarm on the presence and ill effects of counterfeit drugs.
- Philippines collaborated with other organizations to press for a Cheaper Medicines Law and amend the country's patent law.
- Europe worked together with diverse stakeholders to negotiate for lower drug prices; push for the development of new, more effective drugs; strengthen health regulations and mechanisms and scale up research and clinical trials.
- USA mobilized resources to alert the public and their local congressmen to the impending depletion of stocks of methotrexate.

### Way Forward

Mobilize and collaborate with multi-sectoral stakeholders to ensure the presence of policies, programs, and resources for improved availability and accessibility to safe, affordable, effective, essential medicines, and easy access to information on availability and prices of childhood cancer drugs across countries.



## 3. Key Challenges

Pain in children with cancer is often treated inadequately. Unrelieved pain places enormous emotional stress on children and their families. In December 1998, WHO issued guidelines which emphasized that pain relief is an integral part of childhood cancer treatment. WHO stated that non-pharmacological or psycho-social interventions must be part of cancer pain treatment in children. However 13 years later much still needs to be done because of among others:

- myths about pain management as well as the use of opioids and possible "addiction"
- lack of appropriate knowledge of pain assessment tools
- lack of understanding of how children perceive and experience pain
- lack of knowledge of levels of care: hospital – community – home care

### What ICCCPO has done

ICCCPO and members offer innovative psycho-social and other initiatives to improve pain care management:

- Provided child friendly materials explaining procedures children undergo.
- Introduced art and recreational therapy.
- Gave children "beads of courage" for every painful procedure undergone.
- Provided simple practical tools to care givers and parents for pain management
- Provided practical assistance as well as opioids wherever necessary.
- Advocated for the supply and increased use of opioids in hospitals.

### Way Forward

Collaborate with WHO, SIOP and other pain care associations to ensure that WHO guidelines are updated and fully implemented, identify cost effective options for low resource countries and include families in pain care management decisions.