

Mobilizing for Childhood Cancer as a Non-Communicable Disease



This document has been prepared by the International Confederation of Childhood Cancer Parent Organisations (ICCCPO) to inform members groups of ongoing global discussions on Non Communicable Diseases (NCDs) prior to the UN Summit on Non-Communicable Diseases (NCDs) to be held at UN Headquarters in New York City in September 2011. It is **intended that this material will provide member organizations with basic knowledge and information on NCDs which will help them to pursue conversations and clarify their own thoughts on whom to engage in developing a strategy in their own countries.**

June 2011

I. Meeting on NCD's

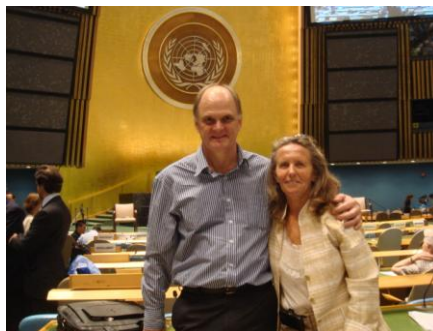
On 13 May 2010, the **UN General Assembly unanimously passed a resolution to hold a UN Summit on Non-Communicable Diseases (NCDs)** in September 2011, at UN Headquarters in New York City,. The UN Summit on NCDs is the **second of its kind** to focus on a global disease issue. The first UN Summit related to health was the HIV/AIDS meeting in 2001 which led to the creation of the Global Fund.

The NCD Summit will focus on the four most prevalent non-communicable diseases, namely, **cancers**, cardiovascular diseases, chronic respiratory diseases and diabetes, with the aim of reaching an agreement among member states on a global strategy to address NCDs.

Since an NCD Declaration will serve as a reference document for the UN, meetings in every region of the world have been held to prepare statements of desirable outcomes. The WHO is drafting the official UN Outcomes Statement, due out late in June 2011, which is to be circulated to all UN Member States; this will be put to a vote of acceptance by heads of states at the UN Summit in September.

To hear the voice of multi-stakeholders, an Informal Interactive Hearing on NCDs, was held on 16 June 2011, at the UN in New York. 350 representatives from civil society organizations, NGOs, NPOs (non-profit organizations), who have set up Alliances on NCDs, private corporations and academia were in attendance. Two members of the ICCCPO board, Kenneth Dollman and Edith Grynspanholc, as well as ICCCPO member from the USA, the American Childhood Cancer Organisation, represented by their Executive Director, Ruth Hoffman, attended the session to present a case for childhood cancer. Kenneth and Edith distributed a prepared press release on childhood cancer for other delegates in attendance.

Princess Dina Mired from Jordan, the director of the King Hussein Cancer Foundation, in her address pointed out that *“whether an individual survives or dies from an NCD depends on in which country a person is born.”* She used as an example the situation in Jordan at the time when her young son was diagnosed with Leukemia, where there was no facility available for treatment of childhood cancer and they had to go to the USA for treatment. She went on to highlight that *“a lack of attention to NCDs has made it a “non-communicated” disease”*.



Why is the NCD Summit important?

The Summit is the best opportunity to put NCDs on the global agenda. It has the potential to mobilize and secure commitments from Heads of Government, for a coordinated global response to NCDs, substantially increase financial resources for NCDs and save millions from premature death and debilitating health complications. It can also lead to measurable targets that can be monitored and for which governments can be held accountable through regular reporting. It also offers an invaluable opportunity to coordinate work against cancer on a global scale and to ensure that the voices of those with non-preventable cancers, such as childhood cancers, are listened to , given due importance and not ignored

Acceptance of NCD's as a Millennium Development Goal could lead to the future earmarking of overseas development funds to address cancer and other NCDs in developing countries.

II. NCDs: A Growing Global Health Threat

- **What are NCDs**

A *non-communicable Disease* is a disease that is not spread through contact or germs. It is caused by how people live (e.g. harmful lifestyle behavior), conditions that they are born with (either genetic, inherited or due to unknown causes), or exposure to environmental hazards (e.g. second hand smoke, fumes, toxic substances etc.).

The main lifestyle related risk factors of NCDs are tobacco use, inadequate eating habits, physical inactivity and alcohol misuse, all of which are avoidable and preventable social determinants that also increase high blood pressure, dyslipidemia and obesity.

- **Why should the world take notice of NCDs?**

“To do justice by our duty as the voice of all those who have been affected by NCDs, and to protect the lives of all those who will be affected by them in the coming years, we need to ensure that NCDs receive a new label marked “urgent action required now.” Her Royal Highness, Princess Mired.

The WHO has identified the following chronic diseases as the main threats to human health: cardiovascular diseases, cancer, diabetes and chronic respiratory diseases: *“These four diseases are the main causes of death and disability worldwide, representing about 60% of deaths and 44% of early deaths (35 Million deaths every year, 80% of which occur in low and middle income countries”*

NCDs represent a serious public health issue and are a health emergency worldwide. Deaths from NCDs are rising quicker in Africa than in the rest of the world (27%), with the Eastern Mediterranean region (25%) a close second. The highest absolute number of deaths will occur in the Western Pacific and South-East Asia regions. In spite of the severity of the situation and the enormous strain they have on health systems worldwide, the funding to fight NCDs is only 1% of the total funding that is dedicated to development.

The negative impact of NCDs has increased due to urbanization, the modifications of lifestyles, growing reach and power of corporations that promote the use of harmful substances (unhealthy food, etc), social inequality and poverty, difficulty in access to affordable health systems, and political and social inaction.

NCDs deepen social inequality since they have a greater impact on poor, less educated people, members of certain ethnic groups, women, children and the elderly, all of whom have lower access to health services, thus hindering human development, counteracting the efforts in the fight against poverty and increasing health inequalities. Despite this, NCDs are still not part of the political agenda of most countries and the Millennium Development Goals.

Prevention and control of NCDs is not only a health strategy, but also a development intervention as a key action in ensuring sustainable human rights and human development. There are several international treaties in which States have assumed obligations and commitments to guarantee essential human rights that are directly connected to the prevention and control of NCDs. However, implementation of these treaties is insufficient.

Some Ministers from National Health Department have made comments like: “Health systems are nearly bankrupt and prevention on NCD’s is the solution” and “because of the current economic situation it is necessary to prioritize prevention”. There is as a result, an emerging tension in 2011 between those who believe that such a meeting should concentrate on prevention and those who believe that support and research for a cure for NCDs is also crucial.

While a focus on prevention, where possible, is necessary, it is vital that similar importance be given to research and to providing affordable, accessible, quality care for patients already suffering from cancer as well as for those suffering unpreventable cancers.

III. Childhood Cancer : An even more neglected NCD.



- **Why should childhood cancer be viewed as an important NCD?**

Children comprise an important and vulnerable sector of society.

Childhood cancer cannot be prevented; it is not the fault and may not be blamed on the parents or the family. It selects children indiscriminately regardless of race, colour, creed, living conditions or wealth.

Death from childhood cancer can, however, be prevented.

Among 5-14 year olds, childhood cancer is the: #2 cause of death in wealthy countries, #3 cause of death in upper-middle income countries, #4 cause of death in lower middle-income countries, and #8 cause of death in low-income countries.

Perhaps more than any other NCD, **childhood cancer is a stark reminder of the human cost of entrenched global health inequities.** In developed countries, where those affected have access to highly developed treatment protocols and well-trained medical staff, 85% of children survive. However, children with cancer who live in resource-poor countries have to contend with: absence of specialist treatment facilities for childhood cancer, lack of health professionals with expertise in childhood cancer, extremely high cost of medicines and treatment, late or incorrect diagnosis, and of the small minority that are diagnosed correctly, only about 15% survive .

Despite the glaring global inequalities, **childhood cancers in lower and middle-income countries,** where 88% of the world's children live, **receive little attention from researchers and health authorities.**

Even from a purely financial standpoint, investment in childhood cancer treatment makes sense as the number of life years saved by survivors of childhood cancers is very high and these children go on to become productive members of society contributing to the well-being of their communities and their own families. Cost of treatment of childhood cancer is also usually less than for adults.

IV. Way Forward

We urge our members worldwide to reach out to their own countries' delegates who will be attending the UN Summit on Non-Communicable Diseases (NCDs) in New York in September 2011, to find out what actions are being initiated in their country in preparation for the NCD UN Summit . We further urge you to engage and dialogue with elected officials, key stakeholders and opinion makers in your country, and to persuade them to adopt an Agenda for Action that will address childhood cancer as an important NCD.

Note: ICCCPO will be sending out additional materials to assist in this process shortly .

For further information on NCD's visit:

NCD Alliance. www.ncdalliance.org

Key Documents: NCD Alliance Briefing Paper on Children and NCD; Don't Forget the Children : A Focus on Children and NCDs; WHO Global Status Report on NCDs; UN Secretary Generals Report on NCDs; Africa's Neglected Epidemic; Moscow Ministerial Conference Declaration; Jakarta Declaration; Korea Declaration; Web casts of UN Informal Interactive Sessions

International Union Against Cancer. www.uicc.org/NCD

Key Documents:

UICC UN Summit on NCDs Cancer Outcomes Statement
Time to Act: The Global Emergency of Non Communicable Diseases

World Health Organization. www.who.org/nmh

Key Documents:

WHO Global Health Strategy for the Prevention and Control of NCD
WHO ACTION PLAN FOR NCDs
WHO 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Non-communicable Diseases: www.who.int/nmh/en/