



Post UN NCD Summit Update

To: ICCCPO Members and Friends

The political declaration of the High-level Meeting of the United Nations General Assembly on the Prevention and Control of Non-communicable Diseases was endorsed by UN member states on 19th September 2011. While not binding under international law, a Political Declaration is considered to be one of the most powerful tools within the UN for international cooperation and action. It will include a set of commitments agreed by world leaders, and backed up by accountability and follow-up mechanisms. This is expected to generate momentum in the fight against NCDs, as well as speed up progress, as previously demonstrated by the Political Declaration on HIV/AIDS in 2001.

ICCCPO, conferred with UN ECOSOC Special NGO Consultative Status, was invited to attend the UN NCD High-level Meeting and nominated two representatives, Edith Grynspancholz and Benson Pau to attend the Meeting at the UN Headquarters in New York. Both of them actively participated in various strategic side events before and during the UN NCD Summit. On 28th and 29th September, Benson Pau also paid follow up visits to Geneva and had discussions with International Federation of Red Cross (IFRC), Union for International Cancer Control (UICC), [SIOP](#), and [WHO](#).



ICCCPO-SIOP side event participants
on 18th Sep 2011



Benson Pau and Edith Grynspancholz
at the UN Headquarters



Ruth Hoffman, ACCO USA with
Benson and Edith

Our attendance in the events as listed below served as a valuable platform for international networking, as well as for building personal contacts with senior representatives from international donor organizations and internationally accredited Non-Government Organisations (NGOs). This also helped to increase both recognition and visibility of ICCCPO.



Date (Year 2011)	Activities made by Benson and/or Edith in New York, USA	Lead Organizer(s)
17 th Sep	From Advocacy to Action: NCD Alliance NGO Briefing for UN HLM on NCDs	NCD Alliance (NCDA)
18 th Sep	Focus group discussion on the Positioning of Childhood Cancer within the NCD hierarchy	ICCCPO, SIOP
18 th Sep	Tackling NCDs: How can existing platforms be leveraged?	Global Health Council
18 th Sep	Scaling up action to curb NCDs: How much will it cost and what is the cost of inaction?	WHO, WEF
18 th Sep	Child Focused Working Group (CFWG) happy hour casual meeting	NCD Alliance
19 th Sep	UN Summit on NCDs Opening Plenary session, Plenary session in the afternoon, Round Table 2	UN
19 th Sep	What gets measured, gets done – Targets & Indicators for NCDs	WHO
19 th Sep	The Role of Universal Health Coverage in Tackling NCDs	WHO & others
20 th Sep	Promoting Access to Essential Drugs at Home & in the Global South: Policy approaches & South-South Cooperation event	UNDP
21 st Sep	Debriefing session: Observations sharing and Scoping out future action	NCD Alliance

Within this short period of time, ICCCPO in conjunction with SIOP was able to arrange a small side event focusing on issues of childhood cancer. This meeting was, attended by representatives from major organizations such as: the UICC, the Max Foundation, NCDA CFWG, Pan America Health Organization. Together with Edith Grynszpancholic and Benson Pau, attendees discussed and exchanged updates on the overall NCD macro-situation, where childhood cancer is positioned and how NGOs intend to advocate for and influence the outcome and future measures on the Political Declaration on NCD Prevention and Control (as illustrated in Appendix 1).

Our participation in these side events and the advice we received during our visits to Geneva, has enabled access to the latest updated situation and a more complete picture of the overall NCD global agenda. It also helped us identify pathways on how we can more strategically and effectively position childhood cancer in the global health and development arena. Hereunder are our observations and recommendations:-

Observations on Key Issues in NCD Declaration and Implications for Advocacy and Action

1. NCD FOCUS

The overall primary focus of the global NCD campaigns will be on prevention and



promotion of healthy lifestyle.

- There is a willingness on the part of most governments to use tax measures on tobacco or sugar as a means to control and prevent NCDs. This is easy to understand as such measures generate increased income/revenue for governments while benefitting society as a whole. This is a win-win solution particularly in times of global economic downturn.

2. ABSENCE OF CHILDREN WITH CANCER IN DECLARATION

Children with cancer and childhood cancer is not yet explicitly recognized nor specifically referred to in the declaration.

- Despite this omission, there is reason to be hopeful. One of the few targets in the Declaration commits governments to establish or strengthen multi-sectoral National Policies and Plans on NCDs by 2013 and to integrate these into health planning processes and the national development agenda. Since this does not specify the focus and scope of these plans, this is a window of opportunity for childhood cancer groups, like us, to work with our governments, relevant offices in the Ministry of Health and civil society organizations, in order to integrate and mainstream childhood cancer issues and concerns. This commitment will hopefully encourage countries with no national plans on Cancer to quickly establish them within the set timetable and for others to revisit and enhance their existing plans.

3. PRIORITY ACTION AREAS

3.1 The need to pursue “comprehensive strengthening of healthcare systems” was highlighted in the Political Declaration. As part of a functional and robust healthcare system and services, the Declaration underscored the importance of:

- Providing universal coverage in national health systems, particularly through primary healthcare and social protection mechanisms, especially for the poorest segments of the population. The use of the term ‘universal’ is most significant especially for low resource and developing countries where insurance is absent or limited in nature and coverage.
- Strengthening information systems and the development of population-based national registries and surveys. This is important especially with countries that have no cancer registries and/or have weak/limited information systems and registries.



GAP: Unfortunately, the SIOP and ICCCPO proposed action of making childhood cancer a notifiable disease such that doctors and pathologists are compelled to report incidence/cases of childhood cancer, was not yet made part of the declaration. This is a necessary action we need to pursue at the local level as without these, childhood cancer statistics will continue to be incomplete and inaccurate, especially in many low resource and developing countries, and we will be unable to capture the whole extent of the childhood cancer burden globally.

3.2 There were clear cut directives for countries to:

- increase and prioritize budgetary allocations for NCD.
- give greater priority to surveillance, early detection, screening, diagnosis and treatment of non-communicable diseases, and the related care and support, including palliative care.
- improve the accessibility to the safe, affordable, effective and quality medicines and technologies to diagnose and to treat NCDs. However, it was emphasized that this should be “according to national priorities and taking into account national circumstances.”

While some groups see this as a let down, others see this as a door opening for greater advocacy and collaboration in the local, national and sub-national level. It is in effect telling governments “we recognize you have different circumstances, but these are directions we encourage you to take, in alignment with your own national conditions and realities. Work it out among yourselves, with your different stakeholders and find the best strategic fit for your country.” Thus, we can use these statements in the declaration to actively and aggressively demand for increased budget allocations for childhood cancer, establishment of priority programs for early detection, screening, diagnosis and greater accessibility to affordable, effective and quality medicines and technologies.

GAP: The importance of our demand for the creation of childhood cancer wards or the provision for separate, child-centered, childhood cancer units within wards has not yet been recognized in many developing countries. We need to continue to advocate for these at the local and national level.

3.3 On an even more positive note, the Declaration specifies bilateral, multilateral channels (e.g. Overseas Development Assistance, Development Cooperation Agreements), which previously did not include/prioritize NCDs. It also encourages the quality of



development aid to be enhanced through harmonization and alignment with recipient country national priorities and urges international organisations to provide technical assistance and capacity building for NCD organizations working in developing countries. Moreover, the Declaration also calls for increasing and sustained support: human, financial and technical resources, especially among developing countries.

3.4 The Declaration repeatedly calls for multi-sectoral and multi-stakeholder action. In the section on Responding to the Challenge, emphasis was on “whole of government, whole of society “approach. There were several references made to fostering partnerships between government and civil society; strengthening of coordination among stakeholders in order to improve the effectiveness of their efforts; acknowledging the contribution and important role played by all relevant stakeholders, including among others: families, inter-governmental organizations, civil society, voluntary associations; building on the contributions of health related NGOs and patients organizations and promoting the capacity-building of NCD-related NGOs at the national and regional levels, in order to realize their full potential as partners in the prevention and control of non-communicable diseases.

These statements are positive affirmations and recognition that we parent organizations and other associate member organizations have a vital role to play and are to be considered as important partners in the fight against NCD. Further, it opens up opportunities for collaboration, with governments, international organizations and other stakeholders, in capacity development for these organizations and capability building for its members.

GAP: Governments failed to commit to a high-level NCD partnership initiative, involving UN agencies, governments, and civil society to coordinate and drive follow-up action. Instead they are requesting the UN Secretary-General to present them with recommendations in 2012 outlining options for such a UN partnership. This omission calls for continued advocacy on this matter.

4. WINDOW OF OPPORTUNITY

In order to generate momentum and support, childhood cancer groups need to become as visible and powerful a force as women’s groups and tobacco control advocacy networks.



Recommendations to ICCCPO Members and Proposed Way Forward:

1. ICCCPO is now part of the Child Focused Working Group (CFWG) under the NCD Alliance umbrella. We shall keep working with the other members of CFWG for the overall benefit, health and well-being of children. We will keep ICCCPO members informed of further information, events, and proposed actions from CFWG.
2. ICCCPO will continue collaborating with SIOP and members at an international, continental, and country level in the coming years to advocate for childhood cancer. ICCCPO and SIOP intend drafting a joint advocacy plan and will keep members informed.
3. We need to be aware of our individual governments' focus and strategy in prevention and control of NCDs, when considering our future moves. We should find a link between what we are doing/intend to do and what our government's priorities are.
4. ICCCPO members should strive to participate actively in the events of WHO and UN (local, regional and international); with the ultimate objective of bringing attention to childhood cancer and making sure that the voices of children, parents and survivors will be heard loudly and clearly. As ICCCPO has now been conferred UN ECOSOC Special Consultative Status, temporary passes can be arranged to join future NCDs events at UN offices/headquarters.
5. WHO and UN are serving the world through their regional offices and country offices worldwide. We encourage all ICCCPO members to increase interaction with all levels of WHO and UN offices in your countries, by inviting them to attend your activities or by participating in WHO and UN sponsored activities so as to make use of opportunities to advocate for and heighten the awareness of childhood cancer.

HRH Princess Dina Mired of Jordan, in her capacity as UICC Ambassador, was a keynote speaker at the Summit and addressed childhood cancer during the Opening Plenary Meeting, where Her Royal Highness clearly unveiled "the harsh disparity between treatment in the developed (90% cured) and the developing world (90% died)" and urged for "imperative government expenditures" to improve the healthcare system.



We are not alone in facing and fighting for childhood cancer issues. We need to expand and strengthen our linkages and networks with other organizations. We need to create champions who have the ability to mobilize support for childhood cancer as an important NCD.

There is an African saying: If you want to reach your destination quickly, walk alone; if you want to make a difference and leave a legacy, walk and work with others. Let's all walk and work together.

Benson Pau
ICCCPO Chair
on behalf of NCD Advocacy Team

Useful information for NCDs advocacy

- ◆ [Homepage of the UN Summit on the Prevention and Control of NCDs](#)
- ◆ [Political Declaration adopted at the UN High Level Meeting of the General Assembly on the Prevention and Control of NCDs](#)
- ◆ [Meetings of the Governing Bodies of WHO, including the subsidiary organs, 2012](#)
- ◆ [Official website of the NCD Alliance](#)

Below are useful documents related to Childhood Cancer Advocacy, which can be found in ICCCPO website (www.icccpo.org)

- ◆ Mobilizing for Childhood Cancer as a NCD by ICCCPO, June 2011
- ◆ NCD Childhood Cancer Focus Letter for Developed Countries by ICCCPO, August 2011
- ◆ NCD Childhood Cancer Focus Letter for Developing Countries by ICCCPO, August 2011
- ◆ Joint ICCCPO-SIOP letter to NCD Alliance, August 2011
- ◆ Joint Press Release on UN NCD Summit by ICCCPO and SIOP, September 2011
- ◆ Childhood Cancer Consolidated Action Points by ICCCPO, September 2011
- ◆ Opening Remarks delivered by HRH Princess Dina Mired at UN High-Level Meeting on NCDs, September 2011

