

## **Result of the workshop „Learning from each other“**

### **1 Abstract**

The workshop “Learning from each other” was about collaboration and exchange of experience between parent and survivors organizations.

One result is that parent organizations all over the world have very different aims due to the different situations of the social systems in their home countries. These aims include to increase the survival rate as well as optimizing the after care and the support of survivors organizations. The regional/national collaboration of the two organizations may be: the survivors group is supported by the parent organization or the survivors work independently. On the international level, the ICCSN (International Childhood Cancer Survivors Network) is supported by ICCCPPO, the International Confederation of Childhood Cancer Parent Organizations. So far, there are only a few survivors organizations worldwide, but a partnership exchange program should support people who want to establish a group.

### **2 Introduction**

This workshop was held to discuss the importance of sharing experiences and resources and to talk about the advantages of collaboration between parents and survivors. The definitions of ‘parents’ and ‘survivors’ might be important. ‘Parents’ are defined as regional, national and international organizations of parents of children with cancer. The definition of ‘survivors’ is similar, they are also regional, national and international organizations of adults affected by cancer in their childhood.

### **3 Result of the group discussion**

#### **3.1 Regional / national level**

##### **3.1.1 Actual Situation**

To describe the actual situation of Parent and Survivors Organizations it is very important to mention that there is a big difference between developed and developing countries. The main problem is that the survival rates in many developing countries are lower than in developed countries. Therefore, the basic aims of these organizations are to increase the survival rate and help the patients and their families with basic care.

Nevertheless, the representatives of organizations in developing countries are interested in the work of the survivors and wish to collaborate with them.

In countries with survivor groups, there are different organizational types:

The first is an informal network of survivors, sometimes they are supported by Parent Organization, sometimes they aren't.

The next “level” of organization is a formal collaboration of parent and survivor organizations. In some of these countries, the survivors have the possibility to be member of the board of their parent organization.

The third kind would be an independent survivor organization. But there were no representatives of this kind in the workshop in Sao Paulo.

Generally, the number of active survivors is unsteady and there is high fluctuation. In many countries there are only a few active survivors, but in Japan, there are too many wanting to work with the group so that they cannot all be accepted as members.

In the Netherlands for example, the survivors are very active and work together with the parents very well. The survivors in Calgary (Canada) also get support from their parent organization and they give back a lot by being actively involved.

### **3.1.2 Wishes**

The wishes of both, parents and survivors, are very similar. The parents want the survivors to communicate their needs and the survivors want to make their own decisions. Most of the parent organizations would support the survivors groups, but they would need to know what their aims are and where they need support. Moreover, the survivor organization should have a basic structure and representatives of the groups.

## **3.2 International level**

### **3.2.1 Actual Situation**

On the international level there are ICCCPPO (The International Confederation of Childhood Cancer Parent Organizations) and ICCSN (International Childhood Cancer Survivors Network). The annual international meeting is organized by ICCCPPO and the survivors have the possibility to take part in an own program, which they design themselves.

During the conference both organizations basically have their own program, but some of the presentations and workshops are held jointly. The own programs are important for the parents as well as for the survivors, because both groups have in some aspects different interests. Nevertheless, it is important for the parents and the survivors to work together and learn from each other. A good collaboration offers both organizations the possibility to exchange experiences. These experiences could be helpful for the international work as well as for the national and regional work.

### **3.2.2 Future**

For the future a good collaboration is very important in order to learn as much as possible from each other, but not only between parents and survivors, but also among the groups. Otherwise it will not be possible to develop on the international level as well as on the national or regional level.

Especially for the Survivors it is important to get new participants from different countries, because currently there are mostly representatives from the same countries every year. So it seems to be important that existing national survivors groups support other countries to set up a survivor group in their own country. This would be a kind of partnership between two countries. With such a partnership it would be easier to establish a survivors group based on the knowledge how other survivors started their groups and how they are organized now. Moreover, there is always the possibility to ask someone who has more experience.

## **4 Conclusion**

### **4.1 Regional / national level**

The number of survivors depends on the country. In some countries, the survival rate is still very low. That is one reason for the different aims of the parent organizations, which reach from trying to increase the survival rate to optimize the aftercare. In countries with survivors organizations it is recognizable that the number of survivors is unsteady and the fluctuation rate is high.

For the future it is to mention that the survivors should have a basic structure in their organizations and representatives. If the survivor organization is supported by a parent organization it would be important that they communicate their wishes to the parent organization. At least there is the wish of most survivors organizations for more independence.

## **4.2 International level**

On the international level there is an annual conference of ICCCPPO, where the ICCSN has the possibility to take part. At this meeting ICCCPPO and ICCSN have their own programs to exchange their experiences among each other, but there are also some presentations and workshops together to support the collaboration. Good collaboration will be important for the future. Another essential project is going to be the partnership exchange program. In this program, existing survivor organizations will support others who want to establish a new survivor organization or groups in other countries.

## **5 What happened after the workshop?**

After the conference in Sao Paulo, I, Stefanie Liener, stayed for two more months in South America. In November, I met the Argentinean survivors organization called “Generación Vida” in Buenos Aires. We had a very good time together and decided that this is going to be the first partnership: Austrian and Argentinean Survivors working together. I will try to translate some documents, because that could be helpful for them. So, this would be the first step.