HANDBOOK

'Establishing a survivors group and keep it going'

Created by
International Childhood Cancer Survivors Network (ICCSN)
the survivors group within ICCCPO

First edition 03/2013

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Acknowledgement

A first brainstorming workshop was held by Michaela Willi and Sabine Karner at the SIOP\textsuperscript{1} congress 2011 in Auckland (New Zealand). Survivors from Austria, Finland, Germany, Japan, South Korea, Sweden and United Kingdom attended at ICCSN Workshop ‘How to establish a survivors group and keep it going’. The collection of experiences and activities from national survivors groups was in the centre of the workshop.

Two presentations, which were held by Dorothee Schmid at former SIOP congresses, were included in this handbook. These presentations dealt with starting and sustaining a survivors group and the importance of leadership. In a Survivors Groups Questionnaire (2007) ICCCPO\textsuperscript{2} specifically asked for ‘What helps to sustain Survivors Groups’. The outcome of this questionnaire is also included in this handbook.

Additionally, many thanks to those survivors, who have prepared a country report about the structure of their national survivors group.

\textsuperscript{1} SIOP (Société Internationale D’Oncologie Pédiatrique/International Society of Paediatric Oncology): The International Society of Paediatric Oncology (SIOP) was founded in the late 1960’s. It has grown into a dynamic and vibrant global organisation. SIOP has over 900 members worldwide including doctors, nurses, other health-care professionals, scientists and other researchers. Our members are dedicated to increasing knowledge about all aspects of childhood cancer. Our aim is to improve and optimise treatments throughout the world. SIOP’s vision is that no child should die of cancer. www.siop.nl

\textsuperscript{2} ICCCPO (International Confederation of Childhood Cancer Parent Organizations) is a global parent driven organisation. It represents 158 parent organisations in 86 countries worldwide and is the only non-medical worldwide childhood cancer organisation representing families of children with cancer. ICCCPO works in partnership with international organisations (UICC, WHO), governments, policy makers, civil society organisations, health and medical professionals (SIOP and SIOP Europe) to raise awareness and create support for childhood cancer initiatives www.icccpo.org “we care, we share”
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1. Target Readership

The target readership is everybody, who is interested and involved in the establishment of a new childhood cancer survivors group, or who is already part of an existing group and trying to keep a group going. It doesn’t matter if the readers are Long Term Survivors (LTS), parents, doctors, nurses, social workers, friends of affected persons/families or someone else.

ICCCPO published a handbook ‘Your group is not alone’ in 2008. The aim of the ICCCP0 handbook is to support parents and parent groups, especially in developing countries, to establish a new group or to keep the already existing group going. These main objectives are the same as those of the survivors and survivor groups. Therefore, the handbook of the ICCCP0 served as a model for this ICCSN handbook ‘Establishing a survivors group and keep it going’.

2. About the childhood cancer survivors group handbook

The handbook doesn’t offer the one single solution for the establishment of survivors groups or for the leadership to keep a group going. It should be seen as a guide to draw your own conclusions and in consequence, to use this information to set up your own model which fits best.

This handbook can be divided into two parts. The first part deals with establishing a group, explains the necessity of a survivors group, the different possibilities for survivors shows how to raise awareness for the group and how to keep it going. The second part presents already existing groups from all over the world and illustrates that, for instance, the organisational structures or financial situations vary between the groups. Read his handbook to get ideas for your specific local or national situation. On the one hand it can be a good tool for a kick-off meeting if you start a group and on the other hand a good tool if you are redefining the aims and structures of your group.

3. Introduction

The worldwide population counts about 7 billion people and 2.2 billion are children (2011/2012). However, 80% of these children are living in developing countries.

That means: More than 175.000 children are diagnosed with cancer each year worldwide. About 13 out of 100.000 children between 0-15 years get cancer, cancer is the second common cause of death in high and middle income countries (HIC and MIC) and the fourth common cause of death in low income countries (LIC) among 5-14-years old children.

Approximately 70% of childhood cancers are curable if they are diagnosed early enough and treated with the appropriate protocols. But 85% of children diagnosed with cancer live in developing countries and cannot benefit from the advanced medical treatment. As a result 100.000 out of the 175.000 diagnosed children die, because they do not receive the right curative care, only rare palliative care and almost no pain relief.

Nevertheless, the survival rate has improved dramatically in developed countries (such as Europe, the USA, Australia etc.), since the late 60’s.
For many survivors, life after cancer is a big challenge, because they may have to deal with late effects, which can be medical and/or psychosocial topics, which are often not present in the life of a 'normal' child or adolescent.

Therefore, survivors groups are important as support groups for survivors of childhood cancer.

4. Necessity of a survivors group

4.1. Life of childhood cancer survivors

The treatment time has not failed to leave its mark on patients: The patient has to deal with fears and isolation within the social network. Additionally, it is also a time, which can influence family members, friends and relationships and consequently may have effects on the further life. Personal changes should not be underestimated, because the treatment and life after cancer can have effects on the feeling for the own body - as well as on the self-esteem.

There are strong differences in quality of life after suffering from a childhood cancer. Some survivors don’t have any physical or psychosocial late effect, but others have to deal with one or more of them. These physical late effects can range from walking disabilities, living with prosthesis, hormone status and cognitive impairment, less able-bodied, infertility and many others, which differ depending on the illnesses and their treatments. Psychosocial difficulties can appear as social isolation, lack of finding friends, depressions, fatigue, less resilience or having problems finding a job. Additionally, former childhood cancer patients can be confronted with societal barriers, like insurances (don’t get a live insurance, private health insurance etc.), driving licence or disability. These fields show discrimination of survivors in their future life.

These different circumstances affect the desire of a survivor to have more or less contact to other survivors. For some of those it is a possibility to be integrated in a group or have contact to other survivors, and not to have the feeling of being different. The peer group is very important when dealing with the own experiences.

4.2. Aims of survivors groups

Survivors, who are linked and integrated in a survivor network/group or organisation don’t feel alone and find support in dealing with these existing difficulties and barriers. Survivor networks, groups and organisations can be seen as an important and essential support group.

In 2007 ICCCPO designed a Survivors Groups Questionnaire with the focus on 'What helps to sustain Survivors Groups'. CLIC Sargent defined three main topics in the analysis of the questionnaire 'why a survivors group is necessary':

a) 'Social contact': It is very important for childhood cancer survivors not to feel alone, because being part of a group and having a social network of people, who have made similar experiences, might have a positive effect on quality of life. The possibility to get in touch with other survivors, personally or virtually, is necessary.
b) 'Sharing': This is referred to the different ways of exchanging experiences within a group. Share information, share knowledge and get advice from those who had childhood cancer, because this can strengthen childhood cancer survivors. Members of a survivors group feel understood, less alone, and they can strengthen their self-esteem.

c) 'Giving Back': Giving hope to others who are living with cancer is very important for Survivors. One good example is the mentoring program. In some countries former patients visit current patients during their therapy (More information about this project appendix VII on page 43).

4.3. When is a survivors group helpful?

It is a very individual and personal decision for each and every survivor to contact a survivors group. Some may consider it very helpful – others not at all. Nevertheless, the possibility to get in touch with survivors should be available at any time, when requested.

Some survivors want to have contact to other survivors directly after the end of therapy. For those survivors special aftercare camps are offered in many countries. Camps where they can recover, enjoy time, have fun with other survivors and strengthen their self-esteem. Others don’t want to have any contact to other survivors directly after the treatment, they don’t want to hear anything about childhood cancer, children’s hospitals nor other topics involved with cancer. They just want to go back to their normal life.

Years of experiences show that those who don’t want to have contact to survivors directly after the treatment often want to get in touch with other survivors some years later. This could be a point in time where the consequences of the treatment or the view of his/her own life after cancer becomes a topic in their lives.

The contact to other survivors can be supportive for childhood cancer survivors at any time of their lives. Having the possibility to get in touch and exchange experiences (personal, knowledge, or medical) is very important.

A lot of survivors want to have regular contact to other survivors during the year. Especially those, who have to deal with late effects, because they are sometimes confronted with social isolation (very often brain tumour survivors). These circumstances (age, possibilities and quality of life) highlight that there is a high need for survivors networks/groups and organisations within a region or country.

4.4. Who might start a survivors group?

The founding of a survivors group may be initiated by anyone who is interested in this topic. It’s important if this person, is a survivor, a parent, a doctor, a nurse, or any other dedicated person, or if it is a group of people. Survivors are former patients and it is essential to address their needs for involving as many survivors as possible. Moreover, the initiative of survivors themselves shouldn’t be underestimated, because a high need and wish from their side for having a survivors group is very important for the success of the new group. Such a group implies the possibility of exchanging with others, of representing the interests of survivors in the community as well as the accompanied empowerment of every individual member and the whole group itself.
5. Definition and structure of survivors groups

5.1. Definitions

5.1.1. Survivors / Long Term Survivor (LTS)

A survivor is (i) a person, who suffered as a child / an adolescent (0-18 years) or young adult (till 30 years) from a childhood cancer, (ii) a person treated at a children's oncological ward (also includes patients who are older than 18 years). A Long Term Survivor (LTS) is a person who is five years in remission.

5.1.2. Group

A group is a number of individuals working together with a common aim.

5.1.3. Survivors group

A survivors group is a union of survivors, who have commonalities within their group. The group wants to achieve specific defined aims and therefore, it provides different offers. An own structure within a group is needed and has to be defined precisely to enable an efficient working relationship.

A group can be an own organisation, which means being a legal entity (e.g. CanTeen New Zealand) or can be a part of another organisation. There are different possibilities for being part of an organisation: (i) parent organisation, e.g. Germany, Austria and Japan; (ii) hospital (e.g. Germany Prima Klima) or (iii) adult cancer organisation\(^3\). Moreover, groups may also develop, for instance, from being part of an organisation to a legal entity, as the Greek survivors group did.

5.1.4. Network

A network is an interaction of people. It has a loose structure, but with a common aim and regular meetings. A group is a part of a network and the people belong to a group, because of a joint specific reason.

5.1.5. Survivors network

The survivors network consists of many survivors and most of them belong to a specific regional/national survivors group within the network, like being from the same country. The ICCSN is such a network and there it can be seen that it includes people with different nationalities and a lot of different groups, but all have one common aim and also regular meetings, which can be attended by all network members. The aims of the ICCSN might be similar to the aims of regional groups, but they might also differ.

\(^3\)In some countries survivors organisations or groups work more closely to adult cancer organisations, because the activities of the target group are focusing more on teenagers and young adults who have or had cancer. One example is Les Jeunes Solidarité Cancer in France (more information you find under [www.jeunes-solidarite-cancer.org](http://www.jeunes-solidarite-cancer.org)).
5.1.6. Other important definitions

Leadership

Leadership is the art of motivating a group of people to act towards achieving a common goal. The leader is the inspiration and director of the action. She/he is the person in the group that possesses the combination of personality and skills that make others want to follow her/his direction.

Successful leadership – among other things – involves communicating, inspiring and supervising. There are many different ways of leading a group (e.g. the authoritarian leader, the democratic leader, the laissez-fair leader etc.).

Organizer

An organizer is a person of vision, who organizes, is reliable and dependable, open to hard work but still open to learning, listens carefully to others, accountable, studies other organisations, remains grounded in the community, is patient and persistent, speaks in a language that others understand, knows that change can’t be made by a single person alone, and takes care of all group members and teaches others to become organizers.

Some rules for organizers: listen carefully (to music & words, to heart & mind), speak your own truth truthfully, from your own experience, your own knowledge, your own heart (don’t try to be all-wise) and try to get feedback.

Delegation

Delegation is one of the most important leadership skills! Good delegation saves you time, helps people to develop, grooms a successor and motivates. Poor delegation will cause frustration, demotivates and confuses other persons.

9 steps to a successful delegation:
1. Define the task
2. Select the individual or team
3. Assess the ability (& training needs)
4. Explain the reasons for delegating
5. State the required results
6. Consider the resources required
7. Agree on deadlines
8. Support and communicate
9. Feedback on results

Delegation tasks should be SMART or SMARTER:

S: Specific
M: Measurable
A: Agreed
R: Realistic
T: Time bound (time limit)
E: Ethical
R: Recorded
5.2. Structure of a group

The structure is a very important characteristic factor of a group. All existing survivors groups have a different structure, even if they sometime to be similar. A survivors group has to define two different kinds of structures: the structure within the group and the external structure of the survivors group. Both structures vary a lot, but both are very important and influence each other. In particular the external structure affects the internal structure much more.

The following chapter depicts the internal and external structure of a group with descriptions of the structure of different groups. Moreover it includes important definitions of leadership, organizer and delegation.

5.2.1. Internal structure

The internal structure of a group consists of different kinds of members, roles and responsibilities (see figure 1).

Leader group and core group

The smallest subgroup is the leader group, surrounded by the core group, which is in a close relationship to the leader subgroup. Of course it can also be seen that the leader subgroup is a part of the core group. These two subgroups do all the organisational work, as defining the aims of a group. The leader and the core group are the organisational unit of the survivors group and have to carry most of the responsibility within a survivors group. They have to define the name of the group, its aims and of course terms and conditions of the group itself as well as for being a member of the core group. Especially the name and the aims give the group its identity and therefore, they set the way to the future. For a good and professional working relationship and efficient work it is necessary to create guidelines and rules. Moreover, the way of communication and a working plan have to be defined. Also the way of sharing information and the rules for ‘who gets which information’ have to be clarified.

For such a collaboration of different people it is important to introduce an organisational structure within the core group. Everyone has to know his/her responsibilities, the rules of interacting as well as a timeline for their tasks. Above these working members it is essential to have a leader or a small group of leaders. But this implies that it is clearly defined, how a person becomes a leader or a part of the leader group.

A good cooperation of all these core group members and the recruiting of new core group members are on the one hand essential for the development of a group and on the other hand very important for reaching the aims.

Actually, there are a lot of different organisational structures within such core groups of survivors, as illustrated in the next chapter and in the appendix. In some countries this core group acts as umbrella group between small local survivors groups.
Attending members

Attending members are those who are taking profit from the offers, which are provided and arranged by the core group. Nevertheless, these members are very important to spread the message of the group to third parties and other survivors, because this subgroup includes much more members as the core group. It is also very important to offer these members as much information as possible about the core group and their work, to get them interested in the work for your group, and therefore, people of this group can later be recruited to the core group. Nevertheless, members can take care of the chores of a group the more and better information they have.

Here it could be also seen that the core group, including the leader group, is part of the attending members.

Peripheral members

Peripheral members are members, who take the offers of the group irregularly. They do not have so much contact neither to the group nor to their members and accordingly, they are not so involved in the activities. Because of the characteristics of this subgroup it is important to catch them to get more interested and more involved into the group. Therefore, the attending members are very important as well!

All survivors

All survivors are (i) people who suffered as a child / an adolescent (0-18 years) or young adult (till 30 years) from a childhood cancer, (ii) people who are treated at a children’s oncological ward (also includes patients who are older than 18 years). A Long Term Survivor (LTS) is a person who is two years in remission.

Figure 1: The figure illustrates the internal structure of a group.
5.2.2. Different examples for the internal structure

The survivors of Greece have an own constitution and two different kinds of members: survivors and anyone, who wants to support the survivors group or wants to participate. The only difference between these members is that only survivors can elect the board members and only survivors can be board members. The survivors have an annual assembly to define the next years' programme, activities, goals and more. The election of the board members is every two years at the annual assembly as well as the election of the regional representatives (more details appendix III, page 26).

CanTeen New Zealand has three different kinds of members: (i) survivors, (ii) siblings and (iii) bereaved members. The organisation runs 13 branches across New Zealand with an own committee and the branch in Auckland, with the national office, the committee and the Member Advisory Committee. The Leadership of survivors contains the leaders and representatives of the different regions: (i) President/Auckland and Northland Rep, (ii) Vice President/Northern South Island Rep, (iii) Southland Rep, (iv) Central Rep, (v) Otago Rep, (vi) Members in divisionary committees’, (vii) Member advisory committee (more details appendix V, page 37).

The Austrian survivors group consists of one umbrella group and five regional groups, which have a close interaction. The umbrella group has two leaders and the regional groups one or two leaders. To enable a good collaboration and communication between the regional groups and the umbrella group an annual weekend workshop is held (more details appendix I, page 15).

The survivors group of Japan consists of 13 regional groups and all of them do different activities. A meeting for the leaders of the regional groups is once a year (more details appendix IV, page 32).

The German survivors have only individual survivors groups with little interaction between them. But they offer different national activities for survivors and patients, such as a bicycle tour, national young adults meetings, mentoring project and survivors magazine ‘Total normal’ (more details appendix II, page 20).

5.2.3. External structure

Existing survivors groups have different external organisational structures. The external structure is very important for a group and, as already mentioned, it influences the internal structure strongly. The two main classifications for the external structure are being (i) independent or (ii) part of an organisation.

An independent external structure implies to have a very well organized core and leader group. These members take, besides responsibility for all tasks already mentioned in the chapter 'internal structure', additional responsibility for the financial situation of a group. This results in: (i) the core and the leader groups with more members and a lot of personal resources, such as time and knowledge, (ii) core and leader groups with employees or (iii) in core and leaders groups and additional employees. As an example CanTeen New Zealand is has an independent external structure and therefore, they have to have an own office with employees, and not all of them are survivors.

The other kind of external structure is being part of an organisation, such as a parent organisation (Austria, Germany), a hospital (some projects in Germany) or a charity organisation. Being part of an organisation may have the advantage that the core and leader group has no responsibility for the financial situation, but in this way the financial situation of the group is dependent of the umbrella organisation, which may influence the group as well. Another difference within this structure is that one or more members of the survivors group might have a seat within the committee of their umbrella
group or not. The advantage of being part of the committee is to be more present and more influential on decisions of any kind.

Nevertheless, all the different external structures have their advantages and disadvantages, so there is no best solution. It is important to start the group with an external structure, which fits the best at the moment, because this structure of the group can be further developed over the years. For example the Greek survivors group was part of the parent organisation, and by and by the group developed to be an independent organisation with a close contact to the parents group.

5.2.4. Different examples for the external structure

The external structure varies between the survivors groups and in the following chapter different examples are illustrated.

The survivors of Greece and New Zealand run an own independent organisation. The Greek survivors group 'Kyttaro' decided in 2007 to found a national survivors association after being part of parents organisation for years. Nevertheless, the survivors group and parents organisation have a strong interaction, such as sharing the office (more details appendix III, page 26). CanTeen New Zealand is also an independent organisation with a national office and 13 regional branches, spread all over New Zealand and with employees (more details appendix V, page 37).

The Austrian survivors group is part of the Austrian Childhood Cancer Organisation (parents organisation), but has no seat in the committee of the umbrella organisation. This dependence influences the external and internal structure, which is described in more detail in the appendix I (page 15). But also the survivors group of Japan 'Fellow Tomorrow' is part of the parent organisation CCAJ (Children’s Cancer Association of Japan), without being part of their committee (more details appendix IV, page 32).

The German survivors do not run an own survivors organisation, on the contrary they only have different survivors groups all over Germany. Some of these groups are part of parents organisations or part of hospitals (more details appendix II, page 20).

5.3. Levels of collaboration

Collaboration of survivors and survivors groups is very important, even if you want to found a group or if you want to bring together different groups. A good collaboration serves a lot of advantages, because it saves time, resources, supports and moreover it encourages all participants. All survivors and survivors groups have the same or very similar main objective and therefore, collaboration helps everyone, because no one has to reinvent already existing ideas; and new ideas can be more fruitful if a lot of people bring in their experiences. Especially the collaboration of survivors groups within one country helps, because the situations of the groups are very similar and ideas and concepts can be adapted more easily. Moreover, the aim of having a uniform public appearance is achievable and this induces a higher recognition value and a serious representation as a group towards public.
And never forget: Together you can achieve much more than a single person. A group of people has more ideas, more resources, more experiences, much more different skills and much more energy, which helps to encourage each other!

The collaboration of survivors can be obtained at three different levels: regional, national, and international.

5.3.1. Regional level
Regional survivors groups have in many cases an own structure, with defined leaders. These groups offer meetings and activities for survivors on a regional level. Moreover, these groups may also have mentors, who visit children in the hospital and other small projects, maybe in collaboration with the national level.

5.3.2. National level
The survivors group, which is working at the national level is different from the regional level. This group tries to enable a working relationship between the regional groups and offers the regional groups different kinds of resources, such as posters, folders, or a common webpage. Therefore, the aims are also different.

The objectives of the national level are more organisational ones, such as:

− Raising public awareness
− Raising public advocacy
− Organize projects, workshops, training courses, …
− Offer resources, like knowledge, experiences, posters, folders, …
− Share ideas, between regional groups
− Support interaction between groups

Don’t forget the importance of the interaction of regional survivors groups, because this can save time, resources and helps each group!

5.3.3. International level
The third level is the international one. This level has basically the same aims as the national survivors groups. The international meetings encourage survivors of different countries to exchange ideas, experiences, knowledge, and many other resources and to work together. Examples for international meetings are: SIOP congress, ICCCPO meetings (continental and international meetings), ICCSN, and PanCare Europe.
6. Activities of survivors groups

Childhood Cancer parents organisations offer a lot of programmes for families during intensive therapy and after treatment. The activities of a survivor group can be a part of this offer.

As a survivors group it is very important to define which activities should be offered. The activities/programmes should be guided by the needs of survivors in the region/country. But how can survivors perceive their needs? One possibility is a kick-off event, to organise a meeting with survivors, where they can collect and define their wishes, needs and topics they are interested in.

Additionally, it is important to have a look on the resources within the survivors community to offer comprehensive and sustainable programmes for survivors. Who would like to do something? This way everybody can be integrated and the interests of survivors can be taken into account. This step can be a good (pre-) work and sustains a group for the future. Through sharing of duties, the individual group members get a feeling of being important and being an essential part of the group and furthermore, this helps him/her to take over responsibilities.

The following chapters deal with concrete survivors activities, which cover the needs of long term survivors.

6.1. Survivors meetings

Survivors meetings can range from very informal meetings in a pub to meetings in the office of the organisation (parents organisation, survivors organisation or from another charity etc.). It is not recommended that such meetings take place in a hospital, because the atmosphere of a hospital might have effects on individual members, especially if negative experiences are connected with it or if the area induces bad feelings.

The needs of survivors attending survivors meetings can be as follows:

- Exchange experiences
- Get to know other survivors
- Having fun, feeling of `easygoingness´
- Meeting `old´ friends, getting to know new friends, don´t have the feeling of being socially isolated
- Information transfer (next activities, advise, support, …)
- Attractive activities

The exchange of experiences and information can be only between survivors or also, as an additional support, with a facilitator. Sometimes it makes sense to engage a facilitator, who can arrange that everybody is heard and is part of the group. These meetings can focus on a special topic, like illness related or topics, which are currently important for survivors. It is crucial that everybody has the possibility to talk.

Additional issues which have to be considered when organising survivors meetings:

- Budget of the group activities, where to get money from:
  - Budget from the survivors
  - Get sponsoring from a parent organisation
  - Survivors organisation has own funds
The location of the survivors meetings has to be considered, because it is an essential question/issue where the meetings take place:

- Has to be conveniently situated
- Accessible for everyone

Regular survivors meetings and activities within a region can be a good support for survivors. On the one hand for those who want to take part at meetings occasionally and on the other hand for those who haven’t got a lot of social contacts and therefore, the survivors build a stable social network. In both ways survivors activities are a good assistance and support the quality of life of survivors.

### 6.2. Mentoring project

In recent years one project has become more and more interesting and meaningful for survivors – the so called mentoring project or peer support. Former childhood cancer patients become a mentor for current patient in the paediatric oncological ward. They visit patients during their stay in the hospital and serve as an additional dialogue partner for them.

The aim of this project is to exchange experiences about the treatment, social network, school, life priorities, life after cancer and much more. The survivors want to give hope to the patient and support him/her during the treatment. The visit or dialogue should be patient focussed, that means to recognize the needs and topics important for him/her.

The visits to the hospital should be scheduled according to the resources of the survivors. It depends upon the possibilities of the individuals (weekly, every two weeks, once a month), further if it is only personal or also via sms or email etc. It is very important to create a concept at the beginning and also to integrate people, who are helpful in the implementation of the program (childhood cancer parents’ organisations, psychologist in the hospital, physicians, nursing staff ...). One proposal is to make a kick-off meeting with survivors who are interested to start the discussion about how to do it. Additionally, it is very helpful to do this with a facilitator or if there are survivors who have special skills within the survivors groups.

Currently known mentoring programs are offered in Austria, Finland, Germany, Greece, Sweden and The Netherlands. The individual programme (which procedure, how often, how to get in contact etc.) differs between the countries, but the aims are the same.

There is a special training for the survivors in all of these countries, which is based on the needs of the survivors. This means that the survivors themselves are very much involved in the definition of how these courses should look like. A training course can give a lot of support and self-esteem for the survivor when she/he is going back to the hospital.

The main focus of such a training course is based on self-reflection, communication training. Furthermore information about cancer in childhood and adolescents, hospital structure and what has to be considered when going to the hospital (e.g. hygiene) are integrated as well. The duration of a training course differs between the countries and ranges from one/two weekends to eight weekends.

You can find an overview of existing mentoring programmes on the ICCCPO website, under following link [http://cms.onlinebase.nl/userfiles/c1iccpo/file/Comparison_Mentoring_Programm_FINAL.pdf](http://cms.onlinebase.nl/userfiles/c1iccpo/file/Comparison_Mentoring_Programm_FINAL.pdf).
6.3. Advocacy

Survivors and survivors groups are important as interest groups for patients and for survivors of childhood cancer. Beside the organisation of survivors meetings and activities for survivors or patients one special aim of survivors is advocacy. This means to represent the interests and needs of childhood cancer patients and survivors towards parents, doctors, and other people within the paediatric community or general public.

These needs can range from special survivors activities to medical or psychosocial issues (during therapy or much more in the (long-term) follow-up). If survivors groups are a part of the parent organisation there is a possibility that a board of the regional or national parent organisation includes a survivor. Additionally, it is possible that survivors are part of special working or study groups, where they give their input from a (former) patient point of view. Survivors, who get this possibility of representing the needs within such committees, boards, working and/or study groups, can lead to recognition of survivors needs and as well to an empowerment and strengthening of the survivors and survivors group themselves.

6.4. Other activities

Survivors activities can also include the organisation of national survivors symposia’s, where the survivors get special information like medical, psychosocial and legal topics (social law, employment law etc.) from professionals. As well as special socialising survivors activities like going to the cinema, playing games, bowling, going to a Christmas market, visiting a museum or exhibition, painting or sport events can be offered. The needs and wishes of survivors should be in the centre and the group should be open for new ideas of survivors.

The attendance of survivors at international congresses, conferences or meetings is also an important or a good possibility to support the exchange of survivors. The annual SIOP congress (the professional meeting of the society of paediatric oncology) is one of these possibilities. During this congress ICCPO and ICCSN have that own conference programme, where survivors can meet and get latest information about interesting topics within the paediatric oncology.
7. Establishing a survivors group and keep it going (7 Steps WHAT and HOW to do?)

**Step 1: Idea & Find others**

All starts with a good idea and needs people, who are inspired and willing to work together and want to develop a survivors group or want to have the focus on the needs of survivors.

**Step 2: Organisation of a kick-off meeting**

A kick-off workshop or meeting is a good means to invite all the people who are interested and motivated to get active. Therefore, it is necessary to have a time frame of one day, or even better of one weekend to have enough time for focusing on the main topics which should be considered at the beginning. It is useful to have a facilitator, who moderates and sums up the discussions, takes care to stick to the time schedule, mentions issues, and also leads through the topic without getting stuck or off the track. This is very essential for the whole group to achieve more fruitful results. The facilitator can be a survivor if it is someone who has experiences as a trainer or facilitator, or an external person, like a psychologist, social worker or somebody from that field.

It is important to define either a programme or the goals for the kick off meeting to raise the interest of the people and consequently to motivate and persuade them to participate. The meeting offers the possibility to get to know the people and therefore, also the resources and skills of the members become visible. It is advantageous to have a lot of different people offering different skills! The focus of such a meeting should be on defining the name and the aims (which give your group an identity), but also on the structure to enable a good collaboration for the future. Nevertheless, it should be also pinned down, what the group want to offer and how they want to inspire more people to participate.

**Step 3: Exchange and Discussion at Kick-off meeting & Follow-up meetings**

Here you find topics which should/can be addressed at a kick-off meeting and follow-up meetings. Not all can be addressed at one meeting, so it is good to have regular follow-up meetings to work on these issues.

a) **Topic activities:**

- What is the purpose of the group? (aim, vision, mission)
- What do we want to offer? (what activities do we want to offer)
- What are the needs of our members and the needs of the community?

b) **Topic structure:**

- Define a group name!
- Internal structure: who is the leader or core group
- External structure: independent organisation or part of an organisation
- Collaboration: within country, to other survivors groups, stakeholders etc.
- How will we make decisions? (vote, quorum, representation, …)
- Where, when and how often should we meet?
- Who should be included?
- How can the group grow?
- What are our resources? (personally, time-wise, financially, …)
It is advisable to have written reports of every meeting, because this helps those who couldn’t attend the meeting, but also gives the opportunity to look back and resume the already done work. In this context the introduction of so called to-do lists has been proven as very useful, to define who has to do which work and especially until when. The experience shows that a group has their defined long-term goals (what to reach in five years), but also short-term goals for running projects should be introduced. These goals lead the current way of the group and can be seen as sub-goals to the long-term ones, because they help to reach the long-term goals stepwise. Every project or topic needs a certain period of time and within this time it is necessary to define the aims clearly.

**Step 4: Establish a management**

Building a management team within a group allows a more professional and efficient work. Therefore, an organisational structure has to be introduced. This means to define for instance leaders, board members and/or regional structures. Each person has to know his/her role within the group and his/her responsibilities. The next step is the definition of the aims of the group, because these objectives give the group a specific identity and point out the way for the future. Moreover, the creation of guidelines and rules is necessary to have a good working relationship. To enable a good communication between all members, each member should be within easy reach. Further it should be arranged, which information is only for group members and which is also for third parties. Also the definition of a working plan is an important step to reach defined aims.

Currently there are a lot of different organisational structures within survivors groups and some of these are explained in the appendix. Look at these structures and maybe you will find or adapt an already existing one for your group. Using this information may help you to save some time and personal effort and gives you new ideas:

- Define:
  - aims
  - name
  - collaboration for a more professional and efficient work
  - organisational structure (internal, external)
  - who is member
  - leaders for this umbrella group
  - a way of communication
  - working plan
  - member responsibilities within the group (communication)
- Design a corporate identity (logo, slogan etc.)
- Point out the way for the future (short time, long-term goals)
- Set up guidelines and rules for a good working relationship (decision making)
- Arrange sharing of information (communication)

Which way you go depends on the ideas, vision, resources of the people involved, as well as on cultural background and structure within your country. A lot of different organisational structures within survivors groups are possible, you define what fits best for your needs.
Step 5: Public relation & Communication

It is very important for a survivors network/group or organisation that other survivors and professionals within the paediatric oncology field take notice of existing offers for patients and survivors. Communication and public relation should not be underestimated (see below some tips which need to be considered).

Here you find some public relation tools, which will help you to communicate to survivors, the public and others to become aware of survivors activities.

- **Website:** First you have to think about the structure and how you will present the group and the activities and other information to the public.
- **Flyer and poster:** Design a flyer and poster and disseminate it at hospitals, parent organisations, out-patient or long-term follow-up clinics.
- **Writing a letter:** When you are at the beginning and you want to address new survivors, a good possibility is to organise a kick-off event. One possibility is to write a welcome letter to survivors and invite them to a meeting or keep them updated. Additionally, name a contact person, so that people can get in touch immediately or later.
- **Newsletter:** This is a good tool to provide regular news to the survivors and also to the public about what is going on within the survivors group.
- **You can write articles in newspapers** of a regional or national childhood cancer organisation or maybe your group has an own magazine.
- **Social medias:** Nowadays social medias, like facebook and twitter are an easy possibility to get in touch with other survivors. It needs only a few clicks to establish a group on facebook, this gives the possibility to exchange and get in touch with others. **Attention:** please, keep in mind which data and information you reveal, because you don’t know what will happen with the data and who else is reading it. The aim and the decision using facebook as a communication tool for survivors has to be considered carefully!

Step 6: Work with other stakeholders

It is very important to get in touch with people who are working within this field. These are representatives of parent organisations, psychologists, doctors or nursing staff. Your stakeholders are people who may have an interest in what you are doing. For the leader of the survivors group and the core members it is very important to get in touch and create a positive relationship with them. The best way is to arrange a meeting with those people. The personal contact is so important and can help a lot to build up a good relationship. After this step keep everybody informed as much as necessary, but do not overload them. If they get the information about activities etc. they can communicate this offer to others.

Gaining the support of stakeholders provides validation that the intended purpose is important. Their support will come once you have demonstrated that the group is valuable.
Step 7: How to keep a survivors group going?

It is not always easy to keep a survivors group going, it depends on a lot of different factors and some of them cannot be influenced by the group, its leaders, or the board members of a group. These difficulties can range from poor participation at meetings, no contact to other survivors, good attainability of the meetings, size of a country, less numbers of patients who are treated at a hospital, personal reasons like less time or being confronted with other life topics, and much more.

- Changes within a group are normal, new people joining, others leave the group. New skills or ideas come into the group. That’s why it is always good to keep an eye on the goals and aims of a group, maybe they can be re-defined.
- A survivors group should never exclude a survivor! Maybe it needs a different kind of meetings (depends on the needs), with a facilitator or without. Some survivors are socially isolated – need activities.
- The meetings/activities of the group should always be within reach for most survivors and at an adequate time. It is also advantageous if the meetings are regularly, because otherwise survivors might lose their interest in the group.
- A defined room, pub, coffee house, etc. for meetings allows an easier access for new survivors. However, it should be prevented to meet in the hospital, because some survivors do not feel at ease there, and maybe do not want to attend the group because of this reason. Another important component of such meetings is ‘trust’. The participants have to trust each other, because this is an essential reason for attending a meeting and keeps a group going.
- Early announcement of meetings: It might be good to have a yearly schedule of the meetings (when, what and where).
- Ask survivors themselves, which kind of topic/meeting they prefer and would need. Sometimes it is necessary to offer different kinds of meetings, because survivors have various needs and reasons for motivation.
- From the organisational point of view it is always important that a group establishes contact to other groups. The leaders should also try to network with other groups. Workshops are a good tool for interaction between groups. It maybe considered to meet representatives of the regional survivors groups (once or twice a year). As mentioned in the chapters before, good interaction and communication is very fruitful to achieve the aims of a survivors group!
- Another objective fact is that on-going public relation (use any kind of media) and the contact to parents organisations, doctors, nurses, psychologists etc. is very important. The group should be always visible for third parties. This helps the group to be taken seriously, to get a budget from donations or the parents organization, etc. and of course also to recruit new survivors. If you are part of an organization it is always very helpful if you have one contact person and of course if the relationship is a good one, because you should not hesitate to ask this person.
8. Conclusion

Survivors are former patients and it is essential to offer those a platform to exchange their experiences as well as to address their needs, like aftercare programs. Additional, they are very encouraged to share their experiences to support current patients and their families. It is not self-evident that survivors take over a responsibility for the interests of the needs of survivors, nevertheless there are a lot of existing survivors groups all over the world. Therefore, survivors groups/organisations can be seen as an important interest group for patients with childhood cancer and survivors.

Our main objective of this handbook is to give support to survivors and all those people who are interested in establishing a survivors group or keep an already existing group going. The handbook should give everyone in this field a lot of ideas and inspiration. But it depends on the local/regional or cultural situation of your country/region how a survivors group has to be established.

We hope you got some ideas about: (i) the possible structure of survivors groups/organisations, (ii) what activities survivors groups can offer, (iii) the seven steps, which can be considered to get a survivors group going and (iv) some national reports from survivors groups.

Contact:

Do you have any input for this handbook – Did you start working with a survivors group or you have already a survivors group in your country/region? Do you would like to get information about the ICCSN activities? Or do you have any other questions, comments or ideas?

Just write us an e-mail to get in contact and if you are interested in the work of ICCSN we can include your contact details in the mailing list!

We are very interested in your experiences and we are looking forward to get in touch with you!

Jaap DEN HARTOGH, Sabine KARNER, Meike NAAFS, Dorothee SCHMID and Michaela WILLI

International Childhood Cancer Survivors Network (ICCSN) Committee Members

International Confederation of Childhood Cancer Parent Organizations (ICCCPO)

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History of development

In 2003 survivors from Austria participated in an ICCPPO congress for the first time. The exchange with survivors from other countries was very fruitful and motivated all to create similar offers for survivors. This experience encouraged also the Austrian survivors and so they started to be active and established the Austrian survivors network with help of the ‘Austrian Childhood Cancer Organisation’. The first meetings were held in Vienna and afterwards also in Linz and Innsbruck.

During the first years of the network the main focus was on offering regular survivors meetings for the exchange of personal experiences. By and by the number of survivors attending the meetings and at the same time also the variety of activities and programmes increased. The small network quickly developed into a group with an organisational structure.

Meanwhile the Austrian survivors have a range of activities like different kinds of meetings in many Austrian cities, mentoring programs and workshops. Moreover, there are survivors groups in five Austrian cities (six Austrian cities have paediatric oncology wards), Vienna, Innsbruck, Linz, Klagenfurt and Graz (Figure 1).

Figure 1: The Austrian childhood cancer organisations are illustrated by different colours and listed above, the regional locations of survivors groups are marked by flowers.
Organisational structure of the Austrian survivors group

a) Separate organisation or part of an organisation (e.g. parent organisation)

The Austrian survivors group does not run an organisation of its own, it is a group within the 'Austrian Childhood Cancer Organisation' (parents organisation).

For better understanding here is some background information about the structure of the parent organisations in Austria (Figure 2): The structure is federal and similar to the official structure of the state. It consists of the 'Austrian Childhood Cancer Organisation' and six regional organisations which are named by the region for which they are responsible. All childhood cancer organisations are coequal and independent.

The regional childhood cancer organisations are located beside paediatric oncological wards and they are responsible for the area from which the patients come (Figure 1). Their main work is the support of families whose children are in treatment.

The 'Austrian Childhood Cancer Organisation' is the only one which is not directly linked to an oncological ward. The focus of its work is on psychosocial aftercare of children and adolescents and their families on providing information material for concerned families as well as raising awareness, exchange on an international level and political lobbying.

This organisational structure influences the situation and location of survivors groups especially the hierarchy.

Figure 2: The organizational structure of the Austrian survivors and the Austrian childhood cancer organisations and their interactions.
b) Leadership of survivors

The Austrian survivors group has one 'umbrella group' and five regional survivors groups (two groups of these are very new and still in development). Each regional survivor group fits to a regional childhood cancer organisation and the umbrella survivors group belongs to the 'Austrian Childhood Cancer Organisation' (Figure 2).

The umbrella survivors group has two leaders and each regional survivors group has one or two leaders.

From the beginning of the Austrian survivors group a workshop for the leaders of survivors groups is organized annually. It is a very important occasion for sharing activities, ideas, reflection and future plans of survivors work, motivation for group leaders, communication, discussion of problems etc. It is a weekend workshop supported by a facilitator.

The regional groups have a strong interaction with the umbrella survivors group to share experiences and work. This means that the umbrella survivors group supports the regional groups with public relation material like website, leaflets and posters and regional survivors groups exchange mainly ideas, like finding new survivors or offering activities.

c) Target group

The target group of the Austrian survivors are young adults who have had cancer in childhood or adolescence.

d) Aims and principles of the survivors group

− We take care of children and adolescents who have been diagnosed with cancer and give support in handling their situation in treatment as well as after therapy.
− Nobody suffering from cancer should feel alone. To be a survivor means to be a part of a group and everybody should have the possibility to get in touch with other survivors.
− We are focusing on the needs of children and adolescents with cancer. Uncertainty shall be reduced by meetings, talks and exchanging of experiences.
− In our meetings we try to create a friendly, understanding and appreciative atmosphere. Survivors can exchange their thoughts and feelings with others who have made similar experiences.
− We are an interest group for survivors of childhood cancer. Survivors often have to handle late effects – medical and psychosocial – and they have a lot of questions (e.g. to find a job, disability etc.).
Ressources und Infrastructure

a) Activities of survivors groups – what do we offer

Survivors meetings take place in Vienna, Linz and Innsbruck. The monthly meetings are very different and depend on the needs of the survivors and the regional structure. Some survivors meetings take place in a pub and others in the office rooms of the childhood cancer organisation with or without a facilitator. There are also meetings with different activities, like going to the cinema, painting, visiting museums, having picnics, carnival parties, beating drums or sportive activities.

Once a year, a summer party for all Austrian survivors takes place. This meeting is organised each year by a different regional group.

There are also seminars moderated by a facilitator. The aim of these seminars is personal development, strengthening of personality and self-confidence and support of the individual social network.

Since 2004 Austrian survivors visit patients in paediatric oncological wards (Vienna, Innsbruck, Linz and Graz). As a preparation for this task a special mentoring program is offered which consists of several modules: Introduction module (one weekend, 20 hours), self-awareness and psychosocial training (four weekends, 80 hours) and communication training (three weekends, 60 hours). All courses are held by professionals.

b) Communication

- Website – www.survivors.at
- Leaflet
- Poster
- Survivors newsletter
- Facebook group
- Newspaper of childhood cancer organisation

c) Funding and support

The financial situation of each group depends on its local childhood cancer organisation. This means that each group has different financial resources for its survivors activities.
Structure of Survivor Groups and young people seminars in Germany

1. **General Information:**

The German survivors groups do not run an organisation of their own. There is a close connection with the different regional and national parents’ organisations and the hospitals. More than 70 regional parent groups exist in Germany, most of them are member of the umbrella organisation (DLFH) and the German Childhood Cancer Foundation (Kinderkrebsstiftung).

Currently, we do not know how many regional survivors groups exist within Germany. The financial and advisory support is different – some survivors groups have support, others not.

A few national activities for patients and survivors exist in Germany: A bicycle tour, national young adults meetings, mentoring project, Survivors magazine “Total normal” and the “Waldpiraten Camp”, which was founded by the German Childhood Cancer Foundation. More information is available under [www.waldpiraten.de](http://www.waldpiraten.de).

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**Explanation of the Figure:**

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2. National activities for patients and survivors

a) „Young people seminar“ for young adults during and after cancer treatment

Aims and key aspects

The national seminar should give information and support in all questions, which are associated with cancer and disease related handicaps. The aims are to support social integration, personal development and the ability to communicate.

Target audience are young adults during and after cancer treatment

- with health related impairment problems and young adults during the illness who have problems to be integrated into society
- who have no contact and exchange with other affected persons
- who suffer from an illness which caused disability.

Key aspects of the program:

- lectures on medical developments
- lectures on psychosocial standards and therapies as well as requirements for communication with young patients
- development of requirements for long term after care
- use of social media and its implications
- enhancements of the project “Patients help patients” (mentoring programme)
- presentation and practical training of physical activities
- creative and handy crafts workshops
- offering outdoor adventure activities

The presenters of the seminar are therapists and educators. Also Survivors could take over this part, when they have required special knowledge in specific areas of interest. Many survivors are committed to helping patients and survivors with handicaps.

Organisation of the seminar

The invitations will be distributed to:

- young adults, who are in contact with the German Childhood Cancer Foundation
- psychosocial teams in hospitals and rehabilitation clinics
- self-help-groups
- childhood cancer regional parent-groups
- Oncologists in private practice.

Participations fee:

Participation is possible for the majority of young adults. The fee is not too expensive, so that there are no social nor financial obstacles for potential participants. Additionally, refunds for transportation expenses are granted.
**Agenda:**

The seminar contents are discussed with the participants. It is important that the wishes and questions of the participants are in the focus of the seminars.

During the seminars new projects for patients and survivors are developed. Two well known projects are the bicycle-tour and the project “patients help patients”. Some survivors are delegated to the international meetings for Survivors at the annual meeting of “International Confederation of Childhood Cancer Parents Organisation” in cooperation with the SIOP conference.

In general the seminar should enable the participants to take an active part and to advocate for the needs of patients and survivors.

Beside the national young adults seminar there is currently one seminar, which is dealing with one special topic. Examples for the special topic are partnership, sexuality or body attentiveness.

**b) Bicycle tour “Regenbogenfahrt“**

This special bicycle tour exists since 1993. Every year survivors from all parts of Germany participate in the one week long tour. During the tour the participants visit different hospitals, where children and teenagers with cancer are treated. The aims of the survivors are

- giving hope
- to provide examples for life perspectives after successful cancer treatment
- to create public awareness for cancer in young patients

The tour is supported by the German Childhood Cancer Foundation, and sponsored by different bicycle companies and suppliers, German bicycle clubs and a public health insurance company.

More information is available under [http://www.regenbogenfahrt.de/](http://www.regenbogenfahrt.de/)

3. **Regional groups for young Patients and Survivors**

In Germany there are different regional groups for young patients and survivors. In the following two groups will be described, which have a long and differing history. Those two groups can be seen as good examples of the two different organisational structures of survivors groups in Germany. One group was established and is led by survivors, and the other was founded by a parent organisation.
a) Young survivors group organized by survivors supporting other patients and survivors

**History of the group:**

Since 1993, there is a group for young patients and survivors in Heidelberg. A patient had the idea for the group. The young man wanted that the patients keep in touch after the therapy. He and a nurse established the concept for the first meeting. The first meeting should have been a paper chase with different tasks. Unfortunately he died two days before the first meeting. The group started as planned in his memory. The group consist of teenagers with from age 12 and older.

During the years the group grew bigger and the age range became wider. In 1998 the group was split in two groups. There is a group for children and teenager from 9 to 17 years and a group of young adults over 18 years.

**How are the groups organized?**

The leaders of the groups are former patients. Both groups are supported by the regional parents group with financial aid, transportation and facilities. Invitations are sent by email. Both groups have a common homepage.

**How often are the meetings? Which activities are performed by the group?**

Every month the groups have their meeting. Possible activities are: Swimming, trips in the surrounding of Heidelberg, afternoon play session, handicraft work, visits to the theatre, bowling, cooking …

Additionally, the young adult group offers every year a holiday week and a weekend seminar. The weekend seminars have a special topic for example:

- body perception and language,
- advent seminar,
- naturopathic treatment in oncology
- physical fitness after a cancer disease.

More information about the group [http://www.jugendgruppe-hd.de/](http://www.jugendgruppe-hd.de/)

b) Young group lead by the regional parents group

**History of the group:**

Since 12 years, there is a young group in Frankfurt. A nurse of the hospital and a member of the parent group developed the concept. The participants are teenagers from 13 to 22 years. The group is open for siblings.
How is the group organized?

The responsible member of the parent group organizes the meetings. The teenager will be involved in generating the agenda and in the organisation. Every participant is allowed to ask for an activity. If the activity is suitable, it will be part of the program.

The parent group works together with the nurses of the hospital. Using this channel, the information about the young group is spread among the patients. The website is a good source for a variety of information about all aspects of the group.

The parents group gives also financial support for the activities.

How often are the meetings? Which activities are done by the group?

The meetings are monthly. Different institutions offer activities for the group, for example theatre visits, dancing workshops, photo-shootings and much more.

https://www.kinderkrebs-frankfurt.de/gruppen/jugendliche
APPENDIX III

Survivors Greece

Written by Aimilia Tsirou
*Kyttaro*: Greek Survivors Association

*‘Kyttaro’ in Greek means ‘cell’.

**History of development of survivors group**

The roots of Kyttaro go back to the 90s. There was a small group of young and adolescent survivors very active and energetic ‘under the wings’ of the Greek parents association ‘Floga’. We met each other during activities and celebrations organized by ‘Floga’ parents, our parents. Gradually we formed a group, that started setting aims and goals –one of them: a survivors newsletter. Year by year new survivors were joining the group and when, 10 years ago, the ‘House of Floga’ was founded (hostel that provides accommodation for patients and their families who are not citizens of Athens), we started weekly evening visits to the House while we were playing, discussing and spending time with children and adolescents under treatment. Apart from ‘House of Floga’, we were also visiting the Paediatric Oncology Department, mainly on doctors or nurses’ request, in order to support a patient and his/her family (usually the patient and the survivor-visitor had the same diagnosis).

Meanwhile, we (the majority of the survivors) became adults (18+ in Greece). We had developed a life philosophy and cultivated a significant approach as ‘cancer winners’. We started forming new directions for our goals and activities, and wanted to try some ‘new steps’, independently from our parents. At the same time, ‘Floga’ (parents association) decided to be member of a national confederation of parents’ associations when an obstacle emerged. The association’s constitution allowed as members both parents and survivors –in 1982 survival rates were too low- and this was not legally accepted. We were in front of a crucial deci-
sion: the separation of parents and survivors. The logical decision to create a new association, a survivors’ association, emerged. ‘Floga’ promised to support the new survivors association and survivors promised to support ‘Floga’.

In 2007, three survivors managed to gather signatures of 21 survivors who agreed in establishing a survivors association, compose a constitution and make the fundamental statement of establishing a national survivors’ association (within 9 months)! The ‘newborn’ named **Kyttaro**, a name which - apart from its literal meaning (cell) - represents also the dawn of something new. The inspiration for choosing this name for our association is our common belief that “A cell is to be blamed for everything that happened!”

**Organizational structure of survivors group**

- **Separate Organization**

As we referred above, **Kyttaro** is an independent organization that has strong bonds with ‘Floga’ (parents organization). We support each other’s activities and programmes and share offices and secretariat.

- **Leadership of Survivors**

**Kyttaro** has its own constitution which forms the organization’s rules and structure. According to it, we have 2 categories of members: one category includes only the survivors and the other includes any person who wants to support and participate in the organization (siblings, friends, parents, organizations etc). The only difference between the members of these two categories is that survivors ONLY can elect and be elected to the Board. We have an Annual Assembly that examines last year programmes and activities, sets new goals for the next year, programmes and activities, and (every 2 years) elects the organization Board. This Board consists of 5 members and only survivors can be elected. **Kyttaro** is a national association. So during the same Assembly we also elect regional representatives.
○ **Target Group**

The target group of Kyttaro is young adults who have had cancer in childhood or adolescence.

○ **Aims and principles of the survivors group**

Kyttaro aims to:

- support patients of childhood and adolescence cancer and their families
- inform the society about childhood and adolescence cancer
- take care of survivors (considering medical, psychosocial and any other possible aspect) and assure that they enjoy a healthy life

Means of achieving aims:

- ✔ Lobby at the government in assistance with scientific, social and any other corporation that can support us in achieving our aims
- ✔ Contact, communication and collaboration with other associations (national & international level)
- ✔ Organization and implementation of congresses, lectures, publications, exhibitions, gatherings and happenings beneficial for the group
- ✔ Providing support of survivors and their families
- ✔ Sub-committees working on specific matters & problems, developing new ‘approaches’ and offering solutions
- ✔ Creation and development of conditions that allow our aims to come true

**Resources and infrastructure**

○ **Activities of survivors groups – what we offer**

Survivors meetings take place in Athens, in the office rooms of Kyttaro which is shared with the parents organization. We meet at least once a month and we mainly discuss present matters, actions and plans.
Our activities include:

**SUPPORT SECTION**
- Visits at ‘House of Flota’ on a weekly basis
- Visits at Oncology Units in paediatric hospitals (under request)

**INFORMATION SECTION**
- Organising and implementing a congress for the National Day against Childhood Cancer (20.2.2010) with participation of doctors, nurses, psychologists, survivors and families
- Participating in congresses and informative events/ interviews
- (i.e. 8-9/11/012, 8th Seminar for Psychosocial Support of Childhood Cancer Patients and the Family)
- Supporting programmes and activities of the parents’ association (i.e. Barrets Town Camp, seasonal celebrations, special occasions, bazaars)
- Publishing a newsletter

**FUND RAISING SECTION**
- Organizing and holding bazaars (Easter Bazaar in 2011 & plan for Christmas Bazaar in 2012)
- Selling logo products (i.e. pens)

**SURVIVORS’ SECTION**
- Participating in ICCPPO &PanCare meetings
- Participating in Late Effects Clinic (presently paused)

**new INFORMATION & FUND RAISING SECTION**
- Promoting and selling Kyttaro bracelet which ‘represents’ all people who are involved in childhood and adolescence cancer ‘journey’
**Future plans:**

- RE-START a Late Effects Clinic
- ESTABLISH a physicians’ network for survivors
- SUPPORT & INFORM about Survivor’s Passport

  - **Communication**
    - Website – [www.tokyttaro.gr](http://www.tokyttaro.gr)
    - Leaflet
    - Facebook group

  - **Funding and Support**
    (Check Activities)

*Kyttaro* has been acknowledged by the Greek Society of Paediatric Haematology/ Oncology and AKOS Society.

**our MAJOR CONCERN:**

**Adult survivors should not to be isolated or stigmatized**

**but should become both strong and resilient,**

**being able to cultivate a positive attitude!**
1- About” Fellow Tomorrow”

“Fellow Tomorrow” was established 1993.
The group’s name “Fellow Tomorrow” has a wishful meaning of “Let’s make TOMORROW together with FELLOW friends who have the same experiences.”
About 20 survivors are now in our group. We get together every three months and have meetings to share about our problems or do some activities.
Our survivor’s group is under working and has support from the CCAJ.
(Children’s Cancer Association of Japan)
And we also have financial resources and supports from CCAJ.

2- Condition for Participation in FT

There are some conditions in order to participate in FT.

Our group is target for survivors. They must know their condition of the health, and name of his/her diseases and understand the objectives of FT’s activities and also have need to have own intention to participate to our group.
3. **We do activities based on the following three points.**

   **- Make Friends**
   
   We offer chances to meet friends with those who have been having similar experiences.

   **- Exchange Information**
   
   We share experiences of sufferings and concerns.

   **- Approach to Society**
   
   We work collaboratively to inform correct knowledge and understandings of children’s cancer.

4. **Annual Events of FT**

   We have 4 periodic meetings per a year. We hold the general meeting in June every year when CCAJ has the annual meeting. At the meeting, we discuss what kind of events we’ll have and the members who are going to be in charge of activities. In September, December and February we have a regular meeting. By sharing experience we can exchange our own feelings by sharing experiences about disease, and come up with ideas. We think this means “Exchange Information”.

5. **Approach to Society**

   One of our activities is FT members are trying to approach to the society. For example we participate the meeting of ICCPPO. Or to participate the events of companies and talk about our experiences and our activities.
6-Survivors group in Japan

There are 13 survivors’ groups in Japan and each group does their original activities.
One group does survivors’ Camp, the other group does volunteer works at children’s hospital.
Or other groups have discussion meetings on various subjects.
We try to work hard to communicate other survivors by individually and by as a group.

![Our Survivors’ Groups in Japan Diagram]
7. Leader’s Meeting

Leader’s meeting is one of the most important events of survivors group in Japan. This meeting is supported by CCAJ. Once a year each group leaders get together. It was started from 2003, Each year regional group takes charge of the leaders meeting. The group in charge of meeting decides and plans the program of meeting. Each group dose different activities. So we need to talk and exchange information about what we are doing. This is a great help to learn what actives works well and what doesn’t work. At the meetings we discuss “how to invite new members and how to keep them” etc. Often the new comer comes to the group only come once or twice and stops coming. We have to think about that situation seriously. We want to have warm and happy atmosphere which attract both new comers and the current members. We also discuss the difficulty the transition of the leader to the next generation.

8. Our intention

- We hope to approach the general public and to inform about Children’s Cancer. 
- We are trying to support the survivors who have difficulty to join our group. 
- To meet other survivors’ groups is so precious and happy occasion for us. 
- We hope we have more chances and spend more time to be together. 
- Since each survivor’s group has different information, ideas and hopes, we want to exchange those more frequently. 
- We want to support each other and hope to create mutual understandings about surrounding of survivors. 
- We work collaboratively to tell correct knowledge and understanding about children’s cancer.

9. For future

We are very happy to have wider views by attending the international conferences. We are trying to operate our survivors’ network effectively and hope to produce good and fruitful results. We try to exchange more information with international survivor’s networks and bring back and pass them to survivors in Japan. As the Japanese survivors, we want to convey our thoughts and to communicate sincerely and actively with survivors of other countries.
CanTeen New Zealand

History of development

CanTeen was founded in 1988 by Michael Carr-Gregg, who is a childhood cancer survivor from New Zealand, while studying in Sydney.

A youth-oriented cancer patient support group emerged from the personal and professional experiences of Michael Carr-Gregg (pictured above- courtesy of Lawrence Smith/Fairfax Media) who, in 1978 at the age of 20, was diagnosed with a malignant tumour in his neck.

It was his experience of being treated at Wellington Hospital that inspired Michael to form CanTeen Australia while studying there.

Michael's passion was embraced and developed by a group of six young cancer patients and was supported by a number of health professionals.

Not only did young cancer patients need support in their struggle to survive, they needed to escape the pressures of the hospital to simply 'be young people'.

Phillip Townsend, a New Zealand teenage cancer survivor, was visiting Australia when he met Michael Carr-Gregg. After sharing their experiences and learning about the teenage cancer patient support group in Australia, Phillip and Michael decided to bring the concept back home and established CanTeen in New Zealand.

In 1988, CanTeen New Zealand was created to ensure that no young person living in NZ ever has to deal with cancer alone.

The organisation was launched with 'Miles for Smiles', a walk from one end of the country to another to raise funds and awareness of adolescent cancer. Then in 1996 CanTeen was incorporated as a society, and registered as a New Zealand charity.

With the support of health professionals, an endorsement from the Child Cancer Foundation, and the commitment of many volunteers, CanTeen was successful in establishing a national peer support network in New Zealand.

Today, CanTeen NZ operates in 13 branches, North and South Island.
Organisational structure of survivors group

Auckland branch consists of:
- National office of CanTeen and team
- Committee
- Member Advisory Committee

Members are: Survivors
- Siblings
- Breaved members

Across NZ
- Other branches 13
- Committee in each branch
- Staff spread across branches

Leadership of survivors: who represent survivors

- President/Auckland and Northland Rep
- Vice President/Northern South Island Rep
- Southland Rep
- Central Rep
- Otago Rep
- Members in divisionary committees'
- Member advisory committee

Target groups:
CanTeen New Zealand is for supporting survivors 13-24, survivors’ siblings (brothers and sisters) 13-24 and bereaved siblings’13-24. Members are supported up to 25 years of age and leave at this age because members are now fully developed adults.

Aims and principles of survivors groups: any defined goals of the group?

We all have one goal - to represent the members and keep CanTeen doing its job by upholding the six values (Live Life, Keep it Real, One Team, Own It, Respect, Do it Right) and mission statement.

Our Mission is to Support, Develop and Empower young people living with cancer. One of the ways we do this is with our recreational and educational National Programmes.

Resources and infrastructure. Activities of survivors groups – what do we offer

CanTeen provides Summer, Winter and National camps.

National Programmes are generally run over one week at a different city each year around New Zealand. National camp happens once a year and brings together members from all branches.

There have been new weekly activities that have started recently at the start of this year (2012), e.g. DJ school.
Monthly activities to do something outside of CanTeen e.g. Movies, Laser Strike, Paint the Earth (painting of allsorts).

Programmes that run over usually three days into the weekend are art, REAL (Rejuvenated, feel Empowered, gain Awareness and Let Go), Teen Link, leadership, empowering relationships, president and vice president training.

Communication

- Facebook group
- Website: www.canteen.org.nz
- Members 3 monthly newsletter
- National magazine

Funding and support

CanTeen New Zealand does not receive any government funding and we are therefore totally reliant on the generosity of individuals, the community and our partners (donations). Donations received help to provide:

- programmes and activities nationally and regionally
- educational and artistic scholarships
- peer support activities on a local level
- counselling programmes
- hospital and community support
- select research projects to understand factors and increase survival rates and quality of care for all young people in New Zealand
- most importantly fun activities
- The sale of CanTeen Christmas cards, CanTeen's online shop and CanTeen bandanna's also help CanTeen and their members financially.
Survivor Group Alberta (Canada)

The survivors group in Alberta, Canada is currently not active, although there are plans to revive it or start a new one. The original group was started about 5 years ago by former campers (clients) of Kids Cancer Care Foundation of Alberta (KCCFA).

The survivors group was organized with the help of KCCFA staff and seed money. All members are young-adult survivors of childhood-cancer. The executive is voted in by the members. Our primary aim is to remain in touch with other and to offer help and support when a traumatic event happens. We have dealt with the deaths (both cancer related, and other causes), celebrations, and life milestones. We aimed to have semi-annual gatherings to strengthen bonds. However, as the members aged, other life priorities grew more important and that led to the less activities. However, other (younger) members are trying to restart the group.

Besides seed money, there is minimal funding from KCCFA. KCCFA does offer scholarships for which our members have won. Our main methods of communication are email and social media.

Just for information, there are other regional survivors groups in Canada.

For more information, please email the author at leon.lau@gmail.com
Comparison of Mentoring Programs

Sabine Karner, Michaela Willi

October 1, 2012

Introduction

- Aim: to show the differences in already existing mentoring programs
- Six questions were sent to 39 persons from 15 different countries, which were all over the world:
  1) Austria
  2) Germany
  3) Switzerland
  4) The Netherlands
  5) Finland
  6) Sweden
  7) United Kingdom
  8) Ireland
  9) Greece
  10) Italy
  11) Canada
  12) Japan
  13) Hong Kong
  14) Indonesia
  15) Brazil
- After a two week time limit we received answers from people of nine different countries
Results I

- Five organisations of those countries have a kind of mentoring program
- Not all Survivors have the possibility to attend a training before getting in contact with patients
- There are big differences in preparing the Survivors for meeting with patients
  - Some countries have a short introduction
  - Others offer a special mentoring program

First Question:

- Does an offer exist in your country/region/hospital, where Survivors visit patients in the children’s hospital or is there any possibility for patients to get in contact with Survivors?
Results III
Evaluation of the answers

Countries where Survivors visit patients in the children’s hospital

- **Austria**
  - Mentoring patients takes place in three Austrian hospitals (from six hospitals)

- **Finland**
  - In four of five university hospitals peer supporting takes place on a regular basis
  - 5th one in case of need

- **Germany**
  - Have mentors at 16 hospitals in Germany

- **Greece**
  - Visit patients in a weekly basis
  - At the oncological departments of pediatric hospitals and at the House of Children (in one city only)

- **The Netherlands**
  - Mentoring patients takes place in Dutch hospitals

Results IV
Evaluation of the answers

Countries where Survivors don’t visit patients in the children’s hospital

- **Canada**
  - Summer camps
  - No official way to meet a Survivor during treatment
  - The hospital fears that the patients are not ready

- **Japan**
  - It’s not easy to get in contact with patients
  - But some Survivors groups which core with hospitals have the chance to visit patients and do some arts and crafts or chatting with them

- **Sweden**
  - They don’t have this kind of offer in the hospitals yet
  - But it is in development and hopefully starts 2012

- **United Kingdom**
  - Not known, if a mentoring program exists at hospitals in UK
Second Question:

- If yes, do the Survivors get a special preparation/training/course for this activity? Does a special mentoring program exist?

Results V
Evaluation of the answers

Austria
- Have a special mentoring program since 2005
- Everyone who wants to visit patients in the hospital has to attend this
- Obligatory Supervision

Finland
- In Finland there is a training for peer supporters since 2001
- Follow up meetings are twice a year

Germany
- Workshop for one weekend as a basis training at the beginning
- Since 2006
- A second workshop for mentors will be offered 2012

Greece
- No special mentoring program
- If requested will arrange group meetings
- In addition, a young Survivor is accompanied by a more experienced

The Netherlands
- Have a mentor program since 2006
- Have procedures to recruit, select, train and coach Survivors who want to become mentor
- Besides annual training is mandatory for every mentor

Results VI
Evaluation of the answers

Sabine Karner, Michaela Willi
October 1, 2012
Third Question:

- If yes, how does this preparation/training/course look like?

**Structure of the program**
- Consists of eight weekends within one year
- Introduction module
- Self-awareness and psychosocial training
- Communication training

**Costs**
- Mostly financed by the Austrian Childhood Cancer Organisation
- Local Childhood Cancer Organisations pay a fee for participating and the travel costs etc. for the Survivors who come from their district

**Requirements of participation**
- 18 years old and 2 years after the end of the treatment → Preliminary talk
- Mandatory to participate at all weekends

**More Information**
- Two Mentoring Programs were held so far
- The third one for 10 participants has started in January 2011
- 20 mentors finished the program already
Results IX
Evaluation of the answers

FINLAND

Structure of the program
- The training takes two weekends
- Psychological lectures
- Doctor lectures
- Follow up meetings twice a year

Requirements
- 18 years old

Costs
- The finish organization Sylva takes care of all the costs of the training weekends, including the travel costs of the participants

More Information
- Leaders are professionals: They have two leaders, one is a psychologist and the other one is a rehabilitation counselor
- Around 200 Survivors participated the training and 2/3 still work actively as peer supporters.

GERMANY

Structure of the program
- Program exists of one weekend workshop
- Since this year a second workshop for active mentors in
- Workshop includes the following topics:
  - Communication training
  - Self-awareness
  - Organisational questions

Requirements
- Former cancer patient
- 18 years old
- At least 2 years after the end of the treatment

Costs
- The costs for the mentoring weekends are accepted by the German Childhood Cancer Foundation
- But as soon as they are mentors the costs for getting to the hospital are payed by the local parent organisations

More Information
- Coordinated by the German Childhood Cancer Foundation
- One employee of the German Childhood Cancer Foundation and two experienced Survivors are leading the program
- 35 – 40 Survivors attended those workshops
THE NETHERLANDS

Structure of the program
- The Survivors get a training of two days. Subjects are:
  - Family systems
  - Role-playing
  - Individually evaluation of the training
  - Evaluate their perception of becoming a mentor

Requirements
- Age of the Survivors is between 16 and 25
- They had cancer between the age of 8 and 18

Costs
- Payed by the Dutch Childhood Cancer Organisation
- That's about € 22,000 a year

More Information
- Leader of the program: Meike Naafs (Survivor), one of the office workers.
  There is a second trainer, Marian Potters
- About 27 Survivors have already attended the program

Results XI
Evaluation of the answers

Fourth Question:

If not, why doesn`t such a preparation or mentoring program exist?

If not, why isn`t there any offer, that Survivors visit patients in the children`s hospital or that patients get in contact with Survivors?
If not, why doesn`t such a preparation or mentoring program exist?

- Greece
  - The main reason seems to be that they never had so many "candidates".
  - They would have the resources and the time
  - Maybe the next step is to organise it better

If not, why isn`t there any offer, that Survivors visit patients in the children`s hospital or that patients get in contact with Survivors?

- Japan
  - One thing is that it is not easy for Survivors to contact or visit patients in hospitals
  - Japan has some problems of telling the truth of cancer.

- Sweden
  - Since last year Cecilia (Survivor), a person from the Swedish childhood cancer association and a nurse have been doing research of the needs of a program like that
  - Have been visiting the Finnish program twice to see how they have built up their courses and how it is working
  - Start a pilot course to try it in 2012
  - Swedish childhood cancer association will also finance it
Fifth Question:

- How and in what form Survivors get in contact with patients?
- How is the communication of this offer?

Results XV
Evaluation of the answers

Results XVI
Evaluation of the answers

- Austria
  - Staff in hospital
  - Representatives of local Childhood Cancer Organisations

- Finland
  - The patient contacts the association
  - Different ways to get stay in contact with the patients

- Germany
  - Staff in hospital
  - Representatives of local Childhood Cancer Foundation

- Greece
  - Mainly get in contact
    - in the hospitals’ House of Children.
    - Meetings at association’s offices / happenings

- The Netherlands
  - Different ways to get in contact with the patients
Sixth Question:

- Are there any other things, which you would like to tell us concerning your mentoring program?

Results XVII
Evaluation of the answers

Results XVIII
Evaluation of the answers

- Austria
  - Now the Survivors are very welcome at the hospital
  - Have Survivors, who might not be able to mentor

- Finland
  - Have a Guide Book for Peer Support Program
    - Role of peer supporter
    - Facts on cancer
    - Cooperation between the hospital and the family

- Germany
  - Dealing with difficult situations is not always easy

- The Netherlands
  - But it’s really worth all the effort and money
  - All the existing and ‘closed’ contacts have been a great success!
Conclusion

- Only in a few countries exists the possibility for patients to meet Survivors
- In most of those countries exists a mentoring program
  - The practical experience shows the importance of such a preparation program
  - It is very useful for the individual growth/development of the Survivor
- Mentoring programs are very different
  - It is visible that the support for the patients is regionally different, this depends e.g. on following factors:
    - How far the hospitals are
    - How many patients are there and at which age
    - Is the hospital willing to offer this for the patients
    - How many mentors are active
- This presentation should help other organisations, who want to establish a mentoring program to give an overview of already existing mentoring programs

Sabine Karner, Michaela Willi    October 1, 2012