

***ICCCPO 2012 Worksop***

***How to get parents involved  
in the organisation***



***Our Experience***



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Chairman***

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## ■ ***Facts about Japan***

- *Land Area=378,000 Km<sup>2</sup> (70%=mountain/inhabitable)  
⇒U.K.:224,820Km<sup>2</sup> (90%=Plain or hill/habitable)*
- *Population=128 million  
⇒U.K.:61.5 million*
- *Ethnic diversity=Almost none*

## ■ ***Facts about Childhood Cancer in Japan***

- *Number of incidence per year =2,000~2,500*
- *Number of children under treatment=15,000~16,000*
- *Number of Hospitals capable of treating Childhood Cancer=about 200*

## ■ *CCAJ/Children's Cancer Association of Japan*

- *CCAJ was founded in 1968 by the efforts of two parents whose children had died of ALL.*
- *They shared not only their grief but also a belief that It is the responsibility of parents:*

- *To pursue activities to eradicate childhood cancer, and to realize a society where no family should suffer difficulties they have experienced.*



***It is an oldest and largest  
Parents Organization in Japan***

## ■ *Some Facts about CCAJ*

- *Headquarter in Tokyo*
- *Branch Office in Osaka*
- *21 Regional Chapters throughout Japan*



- *11 Board of Directors (All volunteers/ Parents:7, Phisicians:2, Others:2)*
- *20 paid staffs in Tokyo & Osaka*
- *21 Regional Chapters are all run by volunteers (parents)*

## ■ *Other FACTS relating CCAJ's activities*

- *Number of parents/supporters paying membership fee of \$25/year or more =2,950*
- *Number of prints of CCAJ's Quarterly Journal=6,500*
- *Subscribers of Quarterly Journal are ;  
Paid Members, Donators, Hospitals, Regional Public Health Centers, Doctors, Nurses and others*
- *Recipients of CCAJ's Financial Help Program=357  
(2011)*

## ■ *CCAJ' activities involving Parents*

### *(At Headquarters Level)*

- *Counseling/advisory service by Social Workers*  
⇒ *In person, by telephone, by letter and by e-mail*
- *Provide advices/helps for smaller parent groups at hospitals*
- *Organize Networking Events for Parent Groups*  
⇒ *For bereaved and for categorical groups (ALL, AML, Brain Tumor etc.)*

## ■ *CCAJ' activities involving Parents*

### ***(At Regional Chapters Level)***

- *Counseling by doctors and social workers*  
⇒ *HQ arrange and dispatch doctors & SWs*
- *Workshops/Lecture Sessions*  
⇒ *Arrangement of Specialists/Lecturer are made either by themselves or with the help of HQ*
- *Peer counseling meetings*

- ***Regional Chapters being very important among various CCAJ's activities***
  
- ***Establishment of regional chapters started in early stage of CCAJ's history***
  - ⇒ ***The first one, Kansai Regional Chapter was established in 1970 two years after the establishment of CCAJ itself.***
  - ⇒ ***There are 47 prefectures in Japan and currently there are 21 regional chapters. (Some chapters cover multiple neighboring prefectures.)***



- *Regional Chapters being very important among various CCAJ's activities*
- *Local Chapters are run all by volunteers*
- *Typically each regional chapter has a **Organizing Committee** of 3~8 members.*
- *Chairman, Vice Chairman and of Accounting Officer of regional charters are **subject to the approval of Board of Directors of CCAJ** and to be nomination by the Chairman of the Board.*
- *Paid staffs (Social Workers and others) provide appropriate helps and advises.*
- *CCAJ HQ also provide subsidies for the budget*

## ■ *Recruiting Parents for Regional Chapters*

### ➤ *Sources of recruiting parents for a new and existing regional chapters are;*

- *Parents who received counseling/advise by social workers through CCAJ's advising program and eventually became members.*
- *Parents who benefitted by Financial Help Program and became members.*

## ■ *Recruiting Parents for Regional Chapters*

- *Parents actively involved in volunteer activities in the regional hospital who are either members of or have contact with CCAJ.*
  - *Introduced by doctors.*
- ⇒ *CCAJ has been commissioned as Secretariat of “Japanese Society of Pediatric Hematology and Oncology” since its founding.*

## ■ *Difficulties in recent years*

### ● *Decrease of new applicant for CCAJ' membership*

➤ *Very limited number of parent who received CCAJ's services apply membership including Financial Help Program.*

⇒ *Notional change of young parents such as; Receiving benefits and contributing something in return is different matter.*

- *Take benefits/services provided by CCAJ as granted.*
- *Lack of notion of reciprocating good will to others.*
- *Even some doctors introduce CCAJ without sincere understanding to its mission.*

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***END***



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