

CCF advocates to ensure improved services and facilities. We represented the childhood cancer patient cohort at the New National Cancer Strategy 2016-2025 working group and during the New National Children's Hospital planning stages.

**Results:** CCF supports all children affected by cancer by working with Ireland's National Paediatric Oncology Centre to introduce and fund psycho-social support programmes including play services, Beads of Courage™ and a complementary therapy services research project. We collaborate with the Irish Cancer Society on provision of information and developing a Parent Peer To Peer Support Programme.

**Conclusion:** By telling our story, this presentation shows how a dedicated parent group has collaborated with medical professionals, policy makers, national and international stakeholders to establish a national paediatric oncology organisation to help ease the trauma and isolation of a childhood cancer diagnosis on children, their families and the wider community.

## CCI: FREE PAPERS SESSION 1

### O-143 | Cancer in Refugee Children in Turkey

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**Background/Objectives:** Treatment of cancer in refugees is of increasing importance, it causes a substantial burden on the health systems of the host countries. We aimed to evaluate the demographic features and outcome of refugee children with cancer, mostly Syrian, treated in Turkey and to evaluate the problems encountered.

**Design/Methods:** A survey on the demographic data, treatment and outcome of cancer in refugee children in Turkey was conducted. The records of refugee children with cancer treated in various regions in Turkey between June 2011 and October 2015 were evaluated retrospectively.

**Results:** Twohundredandtwelve (212) children with cancer treated in 17 centers in 10 cities were evaluated retrospectively, 197 patients were from Syria. Male: female ratio was 1.5. Median age was 5 years (1-17 years). The diagnosis were acute leukaemia in 52 (24.5%), lymphomas in 35 (16.5%), brain tumors in 31 (14.6%), neuroblastoma in 29 (13.6%), bone and soft tissue sarcomas in 34 (16%), Wilms tumour in 13 (6.1%) and other. The frequency of neuroblastomas ( $p < 0.0005$ ) and bone tumors ( $p = 0.0058$ ) in refugee children were higher than in Turkish children. Fifteen patients underwent hematopoietic stem cell transplantation. Most patients (67.6%) were treated in the south and southeast of Turkey close to the border. All treatment for registered refugees has been provided free of charge. 159 (75%) patients are alive, 31 (14.6%) have died, 22 (10.3%) were lost to follow up. The most frequent problems encountered were accommodation, social and psychological problems, language barriers, compliance with therapy and financial problems.

**Conclusion:** The distribution of most types of cancer and preliminary outcome in refugees was similar to children in Turkey. Shelter, hygiene, language barriers, compliance were major problems. Preliminary results of this survey may help to inform future responses in children with cancer who are forced to migration.

### O-144 | Web Based Application for Online Registration and Follow Up of Children with Malignancies and Non-Malignant Hematological Diseases in Vietnam

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**Background/Objectives:** Lund Vietnam Childhood Cancer Program has been active in Vietnam since 2008. We have identified 9 hospitals in 4 cities treating children with malignant diseases. The epidemiology of paediatric malignancies, follow up, and survival data are fragmented. Bringing together institutions and staff dealing with paediatric cancer in one network creates conditions for further development of paediatric oncology in Vietnam.

**Design/Methods:** A web based online registration program was designed. The patients' records contain demographic data and medical information (diagnosis according to ICCC, type and start of treatment). The program permits registration of follow up visits with specification of contact reason and certain events: relapse, abandonment, lost-to-follow-up or death. Electronic transfer of patients between hospitals is possible. Visualization with figures showing real-time registration status and disease distribution, both at the national and local, level is available. Kaplan-Meier survival curves for diagnoses or groups of patient are drawn automatically. A flexible filter and export function is featured. Notifications are generated if the records are not updated for a certain time period.

The database was created to register malignant diseases and was subsequently extended to register children with non-malignant hematological diseases.

The next step is to initiate an inbuilt calendar function that will allow for scheduling of coming visits.

**Results:** The registration was launched on the 1<sup>st</sup> of August 2015 in 9 hospitals. 2,250 children have been registered until March 2016 (66% malignancies, 34% non-malignant hematological diseases, monthly registration ranges from 167 to 482 patients).

**Conclusion:** This is the first nation-wide registry for paediatric haematology and oncology in Vietnam. It can be used by health care providers and policy makers for more efficient allocation of resources.

This registry allows for better control of follow up and may identify main problems influencing the outcome. It is also a ready-to-use platform for future clinical and epidemiological trials.

## CCI: FREE PAPERS SESSION 2

### O-145 | PASTEC: A Prospective, Single-Center, Randomized Cross-Over Trial of Pure Physical Versus Physical/Attentional Activity in Children with Cancer

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**Background/Objectives:** Among disease- or treatment-related long-term effects of childhood cancer, peripheral neuropathies, deficits in global coordination, balance, attention capacity and quality of life have been demonstrated. Several publications mention a potential benefit of physical activity in improving long term outcome of such complications. Our study aimed primarily at evaluating the feasibility of a weekly physical activity program for children with cancer and secondly at assessing if the type of physical activity proposed could impact the pattern of improvement.

**Design/Methods:** We set up a weekly, 1-hour program of physical activity during the school year from August 2015 to June 2016. 24 patients aged 6 to 18 years with various types of tumors were approached and asked to participate. Included patients were separated in two age-groups (6-11 and 12-18 years) and randomized to have either pure physical or physical/attentional activities. After 5 months, patients were crossed-over in the other group. Neurological, coordination, neuropsychological and fitness testing were administered at 4 time-points during the study. Individual distance and speed was recorded at each session by a dedicated camera.

**Results:** As the study is ongoing, most of the evaluation results will only be available after the planned termination in June 2016 and will be analyzed and reported on the final poster. Twenty-three patient on the 24 approached accepted to participate, one dropped off after 2 months. Attendance after 8 months is 81% (SD 15%), which is slightly above the 80% limit that we had set to consider a weekly schedule as feasible.

**Conclusion:** Final results are not yet available as the study termination is planned for June 2016. Attendance after the first part is good at 81% of the sessions. Offering such a program once every two weeks could potentially decrease the burden put on families of a weekly schedule and improve attendance.

### O-146 | Taking One for the Team: Examining the Effects of Childhood Cancer on the Parental Relationship

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**Background/Objectives:** The tone and quality of the parental relationship has profound effects on the physical, emotional, mental, and spiritual health of the child. A child's relationship with parents is often the most significant relationship influencing the child's well being; in fact, this relationship has formative and lasting imprints on a child. The state of the marital relationship itself has impact on the child so attending to the parents' relationship is primary prevention in caring for the child. This study offers a deep understanding of the effects of childhood cancer on the parental relationship.

**Design/Methods:** Data consisted of the content of 24 interviews with a total of 30 participants. Data analysis of the transcribed interviews was conducted using the research method of hermeneutics. Of the interviews, 10 were individuals/couples whose child had died; 7 where the child had lived but was experiencing long term side effects; 7 had a child treated, cured, and living with little to no side effects.