



JOLANTA KWASNIEWSKA'S FOUNDATION  
*Communication Without Barriers*



# **European Standards of Care for Children with Cancer**

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## Foreword

Significant progress has been made in the results of the treatment of cancer in children. The progress was and is possible because of close collaboration amongst paediatric oncology professionals not only within one country, but in all or most of the centres in many countries. One of the conditions to obtain comparable results and common outcomes is that each of the centres participating in clinical trials should meet certain requirements both in terms of infrastructure for medical diagnostics as well as common work practices carried out by health professionals.

While developing the results that have been conducted by multicentre, multinational clinical trials, significant differences were occasionally noticed in therapeutic effects. One additional problem has been identified- the financial conditions of the treatment institutions in which paediatric oncology units operate. Health managers seek solutions to reduce costs and paediatric oncology units are often treated in the same way as other paediatric units. Standards required in these units do not guarantee the proper functioning of paediatric oncology units, as young patients hospitalised for cancer depend upon and require intensive care and constant supervision. Hence, the concept of common standards for paediatric oncology units was identified.

Taking all this into account, in May 2008 the Board of SIOP Europe, the European Society for Paediatric Oncology, decided to prepare a report on the current state and standards of paediatric oncology centres in Europe. For this purpose, a questionnaire was prepared and sent to the representatives of children's oncologists in all European countries. Based on the results obtained from the survey, the SIOPE Board considered that the organisation of a conference was the vital 'next step' in the preparation of a draft document, entitled, "European Standards of Care for Children with Cancer".

Organising the conference was possible due to the enormous dedication and invaluable support of Mrs. Jolanta Kwaśniewska, wife of the former Polish President Aleksander Kwaśniewski. Her Foundation, "Communication Without Barriers" and her team made huge efforts to organise a very successful conference in Warsaw on 14<sup>th</sup> October 2009, which was attended by all the key stakeholders- multidisciplinary professionals, policymakers, patient

and parents groups- from the majority of European countries. During the conference a draft of the document was presented, and as a result of the discussions amongst the stakeholders, the final document has been prepared.

I am very grateful to all members of the SIOPE Board, particularly Past President Prof. Kathy Pritchard Jones and current President, Prof. Ruth Ladenstein, as well as Prof. Gilles Vassal and Prof. Riccardo Riccardi for their excellent contributions and dedication in preparing the standards. I wish to also express my gratitude to many experts - children's oncologists, psychologists, representatives of parent organisations listed at the end of the document, for sending very constructive and indeed crucial conclusions and suggestions, which significantly enriched this document.

I would like to give my special thanks to Magdalena Gwizdak, Ewa Jack-Górska, Anna Jankowska-Drabik, Edel Fitzgerald and Samira Essiaf for their invaluable administrative, editorial and linguistic help.

I am convinced that this common effort will result in a significant improvement in the quality of care for a child with cancer in all European countries.

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## Preamble

Currently, it is possible to successfully cure over 70% of children and adolescents with cancer and for some specific tumours, nearly all of the cases can be cured. However, there remain significant differences in outcomes across Europe. Treatment is intensive, prolonged and complex. Good survival has only been achieved by medical, nursing and allied health professionals working together as a team in appropriate facilities. Such services require adequate financial support. Some essential conditions must be met in order to deliver an optimal service:

- 1 The child or adolescent needs to be diagnosed as quickly as possible in order to provide the greatest chance for cure and full recovery. This requires both the public and family general practitioners to be highly aware of the potential for children and young people to develop cancer. The symptoms and signs associated with cancer need to be recognised both by general practitioners and paediatricians so that there is the shortest symptom interval and no delays in diagnosis and initiation of treatment.
- 2 It has been demonstrated that survival for children with cancer is more likely if they are diagnosed and treated by an expert team of doctors, nurses, and other specialists working within a specialised unit. Such a unit must include trained medical and diagnostic staff, experienced nurses, patient and family support in the form of psychologists, social workers and teachers and the team must be available at all times. In particular, paediatric surgeons, neurosurgeons, anaesthetists, pathologists, specialist nurses, radiotherapy facilities and blood product support must be immediately available with the objective of diagnosing the patient accurately and allowing prompt initiation of appropriate therapy to reduce toxicity and complications as far as is possible.
- 3 All children with cancer should be treated according to the best available treatment protocols. There is general agreement that this is best provided within units that are active in clinical research and cancer registration processes. When available, children should be offered the opportunity to participate in relevant clinical trials that aim to improve the optimal treatment for all children. Where there is uncertainty about the optimal treatment, these trials may be randomised.

The proposal within this document is directed at all those who are responsible for health issues across Europe and particularly within EU Member States. Doctors and nurses working within paediatric oncology units as well as parent organisations, wish to work with health planners, funders and politicians to optimise care.

Clearly, each individual country has its own healthcare system and this will determine the availability of funds as well as the social structure and conditions under which cancer care for children and adolescents is developed. European countries should have National Cancer Plans that contain specific standards for age-appropriate treatment and care for children and adolescents with cancer. There should be an agreed strategy to develop essential standards and resources outlined in this document to ensure consistent care for all patients. Inherent in the development of clinical teams includes the provision of both postgraduate training and consistent, continuous professional development for all staff concerned.

In many European countries, such standards, sometimes still in progress, have been accepted both by the administrative authorities managing and financing the healthcare system and by the institutions responsible for healthcare delivery. Meeting these standards is becoming a requirement for receiving financial resources and is facilitating change management to improve services.

We appeal to all relevant bodies to allow the universal availability of the necessary expertise and infrastructure and ensure equitable access to the best standards of care for all children and adolescents with cancer. The ultimate goal is to guarantee that all young people with cancer have access to the best available diagnostics, treatment and healthcare.

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## Executive Summary

The provision of a comprehensive care system for children and young people who undergo cancer treatment is essential to help the patient make a good recovery and ensure an optimum quality-of-life throughout and subsequent to treatment. The Guidelines outlined in this document represent the *minimum* standards of care that should be carried out and are initially targeted at EU Member States but are not confined to these countries.

- Centres of Excellence and expertise in paediatric oncology that can provide comprehensive multi-disciplinary facilities and optimum standards of care, reflecting the local population and geography, are essential.
- A Childhood Cancer Register is required at national level, based upon the internationally-recognised classification – International Classification of Childhood Cancer ver.3 (ICCC-3). The peculiarities of adolescent cancer need to be taken into account in this regard.
- Each paediatric haematology and/or oncology unit requires a number of standard facilities to cater for patients and their families as well as approved clinical protocols and link-ups with other specialised units should there be a need for further consultation and/or to offer some procedures ('shared care') to patients living close by.
- Each paediatric haematology and/or oncology ward must consist of a minimum number of qualified staff specialised in treating children with cancer. The team must be capable of responding to the various needs of a patient and their family both at the hospitalisation and follow-up stages, i.e. a multi-disciplinary 'care team'. While a core number of staff is always required, a back-up team must also be available including 'on call' doctors.
- The parents of a child with cancer should be afforded comprehensive information on the diagnosis and treatment of their child by staff members including psycho-social advice, and all information and progress-stages should be well-documented and explained clearly to the parents.

- Ongoing professional development for the ‘care team’ should be mandatory. In addition, the role of parent and/or patient organisations in training staff as well as informing patient families should be broadly encouraged.
- Key components of a paediatric haematology and/or oncology unit include inpatient, day ward and outpatient facilities, as well as residential facilities for parents and siblings. In addition to this, time spent at home for the patient should include the support of local social services.
- Treatment of cancer in children and young people is constantly being refined and the best ‘standard of care’ is widely recognised as inclusion in a clinical trial or study, even for newly diagnosed patients. Treatment protocol recommendations need to be regularly updated, consistent with the latest research findings. Optimal treatment should be widely encouraged by the national childhood cancer research network.
- Depending on the country, drugs are covered either by an insurance company or the state. Standard chemotherapy drugs are often administered ‘off label’ to children with cancer purely due to the lack of relevant paediatric studies in the application for the marketing authorisation. Such ‘off label’ drug use must be covered by the usual national health procedures..
- Data management and safety reporting of the therapeutic programme implemented is vital, and appropriately-trained medical staff is required to carry this out.
- Long-term monitoring of the late outcomes of childhood cancer is essential, taking into account not only survival but also quality-of-life and long-term toxicity.
- Each child or young person with cancer and his/her family should be offered psychological support. Planned social and educational care should in addition be made available. Moreover, detailed information on the diagnosis, therapy and overall impact should be discussed but respecting the patient’s age and appropriate to the level of understanding. Post-treatment assistance should also be available to ensure a child’s reintegration into society.

- Should a child become terminally ill, comprehensive palliative care is required through a multidisciplinary hospice team, Communication channels should be created with the treatment team and the new incoming hospice team.
- A hospitalised child and young adult should be endowed with a number of basic rights:
  - Constant and continuous parental involvement
  - Adequate accommodation for parents in hospital
  - Play and education facilities
  - Age-appropriate environment
  - The right to appropriate information
  - A multi-disciplinary treatment team
  - The right to continuity of care
  - The right to privacy
  - Respect for human rights
- Social support for the child and their family should commence at the time of diagnosis and be monitored along the patient pathway throughout treatment.
- The maintenance of ongoing education for the young person treated with cancer is vital to ensure a straightforward return to school for the patient once recovered. The hospital teacher provides a necessary link between the educational development during treatment and the school.
- Parents play a critical role in supporting their child to overcome cancer and need to be supported, with appropriate facilities available to them at the treatment unit. They need to fulfil the role of ‘partners’ in the treatment process of their child.
- Physical rehabilitation is important immediately from diagnosis for a child spending any length of time in hospital undergoing severe treatment.

## **European Standards of Care for Children with Cancer**

### **1 Organising Networks of Comprehensive Care for Children and Adolescents with Cancer and Serious Haematological Diseases within Each Country**

It has been long recognised that optimal care for children, adolescents and young adults with cancer is delivered within centres of excellence usually termed ‘reference’ or principal treatment centres. The teams involved in their care have full diagnostic services, all necessary drugs and supportive care to optimise survival and minimise toxicity readily available to them.

The number and location of these centres of excellence depends on the population and geography of the country. It is estimated that for every one million under-18 year olds, there are approximately 130-150 cases of malignant cancer per year. In order to justify the investment in the multidisciplinary services required to treat childhood cancers, a principal treatment centre would normally see at least 30 new patients a year, though some centres are much larger (up to 200 or more). For very specialised treatments, such as bone marrow transplantation or complex surgery or radiotherapy, there may need to be further specialisation and defined referral pathways from the smaller to the larger principal treatment centres.

Geography also needs to be taken into consideration. To ensure that the patient does not have to travel excessive distances to receive treatment, especially to avail of some aspects of supportive and emergency care, it is possible to create networks of expertise for paediatric oncology. Such systems of ‘shared care’ are well-established in many European countries, whereby the local hospital delivers some aspects of care closer to home, in collaboration with the principal treatment centre.

### **2 National Register of Childhood Cancer**

Universal population-based cancer registration is recommended for all countries worldwide to assist in both the planning of services but also to facilitate research in incidence, survival, mortality and variation from international recorded data.

There is an internationally-recognised classification scheme specific for childhood cancers (International Classification of Childhood Cancer ver.3 – ICC-3), as their different clinical and biological features mean they cannot be classified according to the systems used for adult cancers. This classification scheme should be used by all registries recording data on cancer in children (defined for registration purposes as those aged up to 15 yrs).

Adolescents with cancer present a challenge, as they may have both ‘adult’ and ‘childhood’-type cancers. Accurate tracking of cancer incidence and outcomes in this age group may require specific work.

The content of the dataset that should be regularly recorded for each patient with cancer should be agreed by national cancer registries. They should ensure international comparability of their data and take account of the benefits of participation in comparative outcome projects undertaken at a European level.

### **3 Requirements of a Paediatric Haematology and/or Oncology Unit**

- (i) The unit should be able to provide modern intensity chemotherapy for all childhood cancers and, in some cases, specialised care for specific diagnostic groups, e.g. haematological malignancies and other complex haematological conditions.
- (ii) The unit must be capable of accurately and efficiently diagnosing both leukaemia and solid tumours or be a highly specialised unit for one of the other.
- (iii) All staff involved must have received training and practical experience in the management of children with cancer and leukaemia.
- (iv) There should be a minimum number of cases that a unit sees to remain efficient and competent. This probably equates to at least 30 new cases per year. Staffing levels must be appropriate to enable consistent care of each patient within such a unit.

- (v) There should be systems in place once treatment has finished in order to monitor long-term outcomes.
- (vi) Dedicated facilities should be available for those patients who are at high-risk of infectious complications, particularly those with prolonged neutropenia. The unit should include single or at most two-bedded rooms for the sickest patients and these should be equipped with ensuite washing and toilet facilities. The overall ward should contain designated areas for playing and education. If there is a mixture within the ward of younger patients and teenagers, separate facilities should be available for different age groups, namely pre- and post-puberty.
- (vii) The unit should contain kitchen and bathroom facilities for children's parents, especially if the children are in any form of isolation.
- (viii) Patients receiving short duration chemotherapy in an ambulatory setting should ideally have a separate day ward area. There should be separate rooms including a procedure room and dedicated facilities to store/prepare chemotherapy and for blood sampling.
- (ix) A dedicated clinic should be established, ideally close to the inpatient and day ward area, to provide continuity of care during and after treatment.
- (x) It is essential that a principal treatment centre has access to an intensive care and high-dependency unit with the potential to ventilate, carry out haemodialysis and leukapheresis to support the child through any complications of therapy, ideally without the requirement to transfer the child to a different hospital.
- (xi) There should be immediate access at all times to paediatric surgery, neurosurgery and other specialties e.g. ENT services, to cover emergencies. This includes access to radiotherapy and 24-hour access to diagnostic imaging, under general anaesthesia if required, and appropriate laboratory investigations to cover emergency admissions.
- (xii) Access to all required cytotoxics therapy and supportive medicine should be available on a 24-hour access basis with facilities for preparation of such medicines, supported by an on call pharmacy service.
- (xiii) The unit should have similar availability of blood products especially blood, platelets, and commonly-used protein fractions.
- (xiv) The principal treatment centre would be expected to be able to offer access to high-dose therapy with stem cell transplantation. This could either be available within the centre or, for smaller centres, through an agreed service with a larger

centre. Similar approaches would apply to complex surgical or radiotherapy procedures that require very specialist teams and equipment.

- (xv) The principal treatment centre would be expected to work in partnership with a network of hospitals closer to the patients' homes, to deliver some elements of supportive care and possibly simpler treatments in a 'shared care' model.

#### **4 Recommended staffing levels for the paediatric haematology/oncology ward**

The staffing levels required in the unit should be based on the annual average activity, including bed occupancy, day ward attendees and clinics. The staff of a ward should include:

1. a head paediatric oncologist and head nurse with appropriate deputies;
2. doctors appropriate to the figures outlined below;
3. adequate nurses to cover the workload including a link nurse who provides the link between the treating unit, parents and the local community;
4. psychology service;
5. social workers – numbers determined by patient workload;
6. ward teachers;
7. activity/play therapy;
8. physiotherapy and occupational therapy staff;
9. appropriate laboratory technicians;
10. medical secretaries and data managers;
11. rehabilitation specialists;
12. dieticians.

The principal treatment centre will employ a minimum of two full-time equivalent experienced doctors and two full-time equivalent experienced nurses even when a unit manages the minimum number of 30 new patients per year in order to provide cross-cover during annual leave and absences. Where high-intensity therapy is delivered e.g. within a bone marrow transplant unit, higher senior staff-to-patient ratios may be required.

It is important for those calculating staff numbers to note that where intensive therapy is being delivered, the care required is little short of that normally seen in intensive care units. Further staff time is needed for multi-disciplinary team meetings to discuss individual patient treatment plans and for the frequent communication which patients and their families expect in order to keep them fully informed of what is happening.

A principal treatment centre requires a dedicated 'on call' doctor with specialist knowledge and experience. Although this on call doctor may be someone still in training, it is essential that the fully trained staff will always provide a back-up on call service and be willing to return to the facility in a timely fashion whenever required. Such a requirement for both 'on call' doctors and those who lead the unit means that the number of doctors employed needs to take into consideration the high degree of intensity of this work.

Similarly, for the nursing staff, at least two people within the team should have certified additional training in oncology and haematology or have gained experience of at least five years working in the field. Each nursing shift should have at least two nurses who have received education in the specialty.

The core team of trained specialised doctors and nurses responsible for running and organising the unit should be supported by adequate numbers of staff to cater for the needs of patients and their families both during treatment and in the follow-up phase, including long-term monitoring and support. Adequate time for in-house and external training is essential for all staff. Each individual country should define its own rules, respecting the minimums outlined above related to staff employment ratios in paediatric oncology wards. This should be based on the annual number of patients treated and the complexity of the care provided by the unit.

The team should discuss on a daily basis the progress of each patient being treated currently in the unit with representatives from all relevant disciplines to ensure continuity of care.

At the time of diagnosis, the multidisciplinary team for the unit will need to discuss the diagnosis and the basis on which it is made, the optimum treatment and the total care

package to be delivered. This information must be conveyed to parents and their consent obtained for the proposed plan of action, according to national laws. As appropriate, based on the child's age and understanding, they may also consent or, as a minimum, assent to the therapy.

Each parent – upon receiving the information about the child's planned treatment – should, together with a psychologist, rehabilitation specialist, a therapist and a teacher, prepare a programme outlining the scheduling of the patient's time when on the ward incorporating educational and recreational activities, ensuring that the child does not, even once, stop feeling like a child. There is significant evidence that the participation of the patient in all educational activities conducted by trained teachers helps the treatment and ensures minimal detachment for the child from his/her natural society with normally little substantial educational losses that could not be made up in the future.

If external advice is required for any particular component of the management, this should also be well-documented and explained to the patient and parents. It is essential that there is good consistent documentation of progress through therapy, decision-making and any changes in therapy. Nowadays, medical record documentation can be maintained by appointed medical secretaries or data managers but always under the supervision of fully-trained doctors and nurses.

## **5 Continuous Professional Development**

It should be mandatory that all members of staff undergo continuous professional development and training including access to updates from research and from other specialities regarding optimisation of diagnosis and care. Appropriate resources and time for attendance at training and education meetings must be built into the programme for all staff. It is the centre's responsibility to send doctors and other staff groups to such meetings.

All units should encourage the links with parent/patient organisations and recognise their vital contribution in supporting the parents of newly-diagnosed patients as well as their support of the staff delivering care.

## **6 Components of care in a specialist facility**

The comprehensive care of a child or adolescent with cancer will usually include:

- 1 Inpatient care
- 2 Day ward care
- 3 Outpatient care
- 4 Time at home, which will inevitably involve the cooperation of the general practitioner, the child's school and the community and social services in the local area.
- 5 Residential facilities ('Home from home') for parents and other family members.

## **7 Delivery of Therapy**

- When treating young people with cancer, the best and most up-to-date therapeutic programmes should be implemented, conducted on the basis of multi-centre co-operation. The programmes should be drawn up by multinational expert teams taking into account the results of past clinical research and current knowledge of the cancer's biology, relevant drug pharmacokinetics and known toxicities in children.
- Each country should have a childhood cancer research network that recommends the optimum treatment protocol suitable for each type of cancer and which updates these recommendations on a regular basis, consistent with emerging research findings.
- If the absolute optimal therapy is not yet clear, entry into a clinical trial randomised between the best-known therapy and a new approach is to be encouraged. In each country there will be a research organisation that will produce or recommend such clinical trials in order to optimise care and maximise survival for each tumour type.

- Parental and patient consent/assent will be required should there be participation in any research clinical trial programme, according to national laws.
- Each country has a different way of delivering their health care system. In general either the state itself or insurance institutions and other funders will need to fully refund the costs connected with the implementation of treatment in accordance with the recommended therapeutic programme. Since the registration of drugs for those under 18 years of age has until recently been quite minimal across Europe, the costs of drugs whose use is considered ‘off-label’ will need to be covered by such institutions or the state.
- For some diagnostic situations, particularly the very rare tumours, the only advised option for therapy is according to an expert group recommended protocol. These may be applied in the context of an investigator-led study, which is not regarded as a clinical trial in all EU Member States. Relevant facilities should be made available to support such treatments and registration in multi-national studies. (Appendix 1)
- The centre is obliged to maintain detailed medical documentation of the therapeutic programme, in accordance with national laws, for patients treated on clinical trials. Sufficient resources for data management and safety reporting must be made available to employ a suitable number of qualified staff and ensure adequate staff training.

## **8 Monitoring the late outcomes of cancer**

For childhood cancer survivors, it is very important for there to be appropriate long-term monitoring of outcome including not only survival but also quality of life and documentation of long-term toxicity of the therapy. The programme for any individual of how to follow and at what interval is to be agreed by the team and the family at the time of cessation of treatment, dependent on the risk of recurrence and of recognised toxicity. The nature of follow-up will be subject to the tumour type and the therapy administered. It should not be so intrusive as to negatively influence the ability of the patient to recover from having been diagnosed and treated for cancer.

## 9 Psychological and Psychosocial Care

The diagnosis of a child with cancer is extremely disruptive to the family and puts even the most balanced family into crisis. Treatment produces great changes in daily life and of course impacts physically and psychologically on the child and other members of the family. The diagnosis and treatment frequently lowers the child's self esteem, distances them from peer groups and clearly requires the help, in many cases, of a psychologist. Each child or young person with cancer and his/her family should be offered psychological support.

Such psychosocial support is an integral part of treating children and teenagers with cancer and of their families. Such support will usually require a clinical psychologist, social worker and teacher/play therapist. Occasionally the team also requires a psychiatrist or psycho-therapist, translators where there are language problems and even spiritual guidance for the family to help them through the process. The quality of life of the patient and the family can be greatly assisted by:

- 1 Planned social, psychological and educational care;
- 2 Thorough communication of information about the illness, its treatment and impact on the family;
- 3 Information given to children must be appropriate to their level of understanding;
- 4 Maintenance for the child to remain active and continue life as normal as is possible given the circumstances of the treatment, with encouragement by all the team;
- 5 Once treatment is completed the team has an obligation to ensure that the child reintegrates within school and society in general.

Psychosocial care requires the team to help the patients and their families through all procedures, treatment and where necessary, palliative care, helping them to cope with the stress involved, pre-empting the potential for crises and attempting to maintain a good quality of life throughout.

## **10 Palliative care**

When a child becomes terminally ill it may be appropriate for the child and his/her family to be taken under the care of a multidisciplinary hospice team. In this case, extremely good communication is required between the treatment team and that new incoming team from the hospice.

## **11 The rights of the hospitalised child**

The child who has been hospitalised for cancer within the European Union should have clearly defined rights:

### **1 Constant and continuous parental involvement**

The child has the right to constant parental assistance throughout the process of treatment. The parents play a crucial role in therapy. They are best placed to understand the emotions of their child and with help, to decrease the stress that the child experiences during the treatment. A partnership needs to be developed between the patient, their family and the medical and nursing team in carrying out the “Care Plan”. It is also very important wherever possible to ensure that the patient has continuing contact with siblings and peers in order to, as much as possible, maintain a degree of normality despite the diagnosis of cancer and its treatment.

### **2 Adequate accommodation for parents in hospital**

The parents should be able to be with the child at all times. The ward should contain appropriate facilities: kitchen, bathroom for parents and sleeping accommodation on or very close to the ward. It is important to ensure that parents manage to maintain adequate sleep and rest time in order to be a useful and supportive member of the “Care Team”.

### **3 Play and education facilities**

All children in hospital should have the right not only to education but also to enjoy recreational activities appropriate for their age. These are essential to maintain a degree of normality and to continue the child’s social and educational development throughout their cancer pathway. Within a ward, there must be one room dedicated to

education and a separate room available for relaxation and play. Funds should be available both for materials as well as staff to provide these services.

#### **4 Age-appropriate environment**

It is very important that the child should be in an environment where there are children of his/her own age and stage of development. Therefore, if a wide age range from 0 – 16 or even 18 year olds are managed within a unit, special facilities for older patients should be created separate from those of the younger children. It is not suitable to have a wide age range of patients within the same ward area.

#### **5 The right to appropriate information**

The provision of information should be prioritised, with careful use of appropriate language, in recognition of the reader, i.e. the child and/or their parents, and on the understanding that at times of emotional distress, patients and parents do not always hear what is being said to them. Therefore, repetition of any communication may well be necessary, supported by clear and understandable written information. However, staff must take account of varying levels of literacy and those for whom the national language is not their mother tongue. Supporting written or visual documentation is important but is not a substitute for good, clear, precise oral communication. Any conversations with regard to treatment should be conducted in a separate, private and quiet area which will facilitate good communication and reduce the risk of misunderstanding.

#### **6 A multi-disciplinary treatment team**

Those who are involved in the ongoing development of the child throughout the treatment in hospital include teachers, play therapists, and psychology staff. They must have the required skills and predisposition to help the patients through this time and know that their role is to try to minimise the adverse impact of having a diagnosis of cancer and its treatment on a young child.

#### **7 The right to continuity of care**

The child has the right to continuity of care for the entire process of treatment and to be informed about the long-term health risks of their cancer and its treatment. Continued treatment or follow-up within the same medical centre(s) is encouraged

beyond the normal cut-off age applied to acute paediatrics. There should be agreed arrangements for transition to follow up by adult services when appropriate and necessary.

#### **8 The right to privacy**

It is essential that the privacy of children is respected during their time in hospital. This includes access to 'quiet' rooms for discussions with parents/patients at critical points in the treatment pathway.

#### **9 Respect for human rights**

Cultural, linguistic and racial difference must be respected.

## **12 Social Care**

Social support for the child and their family should commence at the time of diagnosis and be monitored along the patient pathway throughout treatment. Pre-existing social and financial problems of the family should be assessed at diagnosis and form the basis of personalised family support. In hospital, information should be provided about social support, organisations and funding to help the family through the crises. Social services should be able to provide support for patients, siblings and families in general, to compensate for loss of income and increased expenditure at this difficult time. It is also desirable if social support services provide some normality of life through organised activities and potentially family holidays.

Social workers and other organisations who provide social support represent a necessary link between medical and nursing personnel and the families to assist in the completion of the necessary forms in order to obtain financial support, participation in activities that normalise life and in solving social problems. They have a very important role in helping the family to access all forms of support to minimise the disruption imposed by the diagnosis of cancer in a child or young person.

## **13 Education**

Maintenance of ongoing education is critical for both physical and psychological development. School is not only the place for gaining knowledge but also where relationships are developed, values instilled and a patient's confidence is increased. Education needs to be continued whilst the patient is in hospital and must be led by qualified teachers. The educational programme which the child is attaining should be continued. Teachers and social workers can guarantee that this happens by close liaison with the child's school. Once a child returns home and spends more time as an outpatient or a day ward attendee, it is very important for there to be continuity and for the child to return to school as quickly as possible. The hospital teacher can act as the link and liaise with the school to advise on the educational developments that have taken place while the child was hospitalised

## **14 The critical role of parents**

Parents play a critical role in supporting their child in overcoming the disease to get through treatment with minimal psychological effects. They need to help the child to maintain his/her self-esteem, provide a sense of hope and reduce stress as far as possible, maintaining some degree of normality. During the difficult and sometimes traumatic first stage of therapy the parents play a critical role in providing love, support and easing the pain involved in diagnosis and treatment. This is particularly crucial where painful procedures are required or for example when there are nutrition problems and some degree of artificial feeding is required. If a patient is in isolation, this can particularly exacerbate the stress for the young person and the parents can play a critical role in alleviating that. In order to assist the parents in their role it is important that they feel that they are part of the team and they can be supported as they wade through the process of helping their child. In this regard, it is crucial that the appropriate facilities are available, including the provision of a designated area to relax when the child is resting, kitchen facilities, bathroom facilities and the ability to have access to comprehensive, informative literature on the specific illness as well as information on what organisations exist in order to help them through this often traumatic period. Communication is the key to helping the

parents of a sick child. Parents need to feel appreciated and know that the medical and nursing staff considers them as partners in the “Care Team”, playing a vital role in helping the child through the disease.

## **15 Rehabilitation**

If a child is in hospital for any length of time receiving drugs that affect the muscles and in particular the nerves of the lower limbs, they require good stimulus in order to be active, increase mobility and overcome the effects of cytotoxics drugs. Rehabilitation is required immediately from the time of diagnosis through to chemotherapy and any surgery, in an effort to minimise the physical effects of specific cytotoxics and needs to be continued after completion of treatment to minimise long-term toxicity. Again the parents are critical in assisting in this aspect of therapy. The involvement of both physiotherapists and occupational therapists can minimise the longer-term consequences of therapy including the use of time in the gym and assisting in recovery from illnesses such as myopathy and neuropathy. Special attention should be paid to the additional rehabilitation needs of children with brain tumours. These patients may experience a wide range of functional deficits related to the effects of the primary lesion or treatment complications. It is important for the rehabilitation team to work in close coordination with the neuro-oncology team in those cases.

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## Appendix 1

### The list of Clinical Trial Groups in Europe

<b>EIC-NHL (European Intergroup for Childhood Non Hodgkin's Lymphoma)</b> Tumour Type: Childhood Non Hodgkin's lymphoma		<b>1996</b> (Official 2006)
		<b>CT group</b>
<b>Contact/Chair</b>	<b>Patte, Catherine</b> Email: <a href="mailto:catherine.patte@igr.fr">catherine.patte@igr.fr</a> Institution: Institut Gustave Roussy, Villejuif, France	
<b>EORTC childhood leukaemia group</b> Tumour Type: Leukaemia		<b>1981</b>
		<b>CT group</b>
<b>Contact/Chair</b>	<b>Benoit, Yves</b> Email: <a href="mailto:Yves.Benoit@UGent.be">Yves.Benoit@UGent.be</a> Institution: University of Ghent, Belgium	
<b>EpSSG</b> Tumour Type: Soft tissue Sarcoma		<b>2004</b>
		<b>CT group</b>
<b>Contact/Chair</b>	<b>Bisogno, Gianni</b> Email: <a href="mailto:gianni.bisogno@unipd.it">gianni.bisogno@unipd.it</a> Institution: University of Padova, Italy	
<b>EURAMOS</b> Tumour Type: Osteosarcoma		<b>2001</b>
		<b>CT group</b>
<b>Contact/Chair</b>	<b>Bielack, Stefan</b> Email: <a href="mailto:S.Bielack@klinikum-stuttgart.de">S.Bielack@klinikum-stuttgart.de</a> and <a href="mailto:coos@olgahospital-stuttgart.de">coos@olgahospital-stuttgart.de</a> Institution: Cooperative Osteosarkomstudiengruppe COSS, Stuttgart, Germany	
<b>Euro-Ewings</b> Tumour Type: Ewing's Sarcoma		<b>1999</b>
		<b>CT group</b>

<b>Contact/Chair</b>	<b>Juergens,Herbert</b> Email: <a href="mailto:jurgh@mednet.uni-muenster.de">jurgh@mednet.uni-muenster.de</a> or <a href="mailto:Heribert.Juergens@ukmuenster.de">Heribert.Juergens@ukmuenster.de</a> Institution: University of Münster, Münster, Germany
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<b>Histiocyte Society</b> <b>Tumour Type: LCH (Langerhans cell histiocytosis) &amp; HLH (Hemophagocytic lymphohistiocytosis)</b>		<b>CT group</b>
<b>Contact/Chair</b>	<b>Henter, Jan Inge</b> Email: <a href="mailto:Jan-Inge.Henter@ki.se">Jan-Inge.Henter@ki.se</a> Institution: Karolinska Hospital, Stockholm, Sweden	

<b>Hodgkin's Lymphoma Group</b> <b>Tumour Type: Hodgkin's lymphoma</b>		<b>2004 (Official 2006)</b>
		<b>CT group</b>
<b>Contact/Chair</b>	<b>Landman-Parker, Judith</b> Email: <a href="mailto:judith.landman-parker@trs.ap-hop-paris.fr">judith.landman-parker@trs.ap-hop-paris.fr</a> Institution: Hôpital d'enfant Armand Trousseau, Paris, France	

<b>I-BFM group</b> <b>Tumour Type: Leukaemia &amp; Lymphoma</b>		<b>1987</b>
		<b>CT group</b>
<b>Contact/Chair</b>	<b>Schrapppe, Martin</b> Email: <a href="mailto:m.schrapppe@pediatrics.uni-kiel.de">m.schrapppe@pediatrics.uni-kiel.de</a> or <a href="mailto:sekretariat@pediatrics.uni-kiel.de">sekretariat@pediatrics.uni-kiel.de</a> Institution: University of Kiel, Germany	

<b>ITCC</b> <b>Tumour Type: NBL, RMS, EXS, OS, MB, ALL</b>		<b>2003</b>
		<b>CT group</b>
<b>Contact/Chair</b>	<b>Vassal, Gilles</b> Email: <a href="mailto:Gilles.VASSAL@igr.fr">Gilles.VASSAL@igr.fr</a> Institution: Institut Gustave Roussy, Villejuif, France	

<b>SIOP Brain tumour group</b> Tumour Type: Brain Tumours		
		CT group
<b>Contact/Chair</b>	<b>Doz, Francois</b> Email: <a href="mailto:francois.doz@curie.net">francois.doz@curie.net</a> Institution: Institut Curie, France	

<b>SIOP WT</b> Tumour Type: Renal Tumours		1971
		CT group
<b>Contact/Chair</b>	<b>Graf, Norbert</b> Email: <a href="mailto:Norbert.Graf@uniklinikum-saarland.de">Norbert.Graf@uniklinikum-saarland.de</a> Institution: Homburg University, Germany	

<b>SIOPEL</b> Tumour Type: Liver Tumour		1987
		CT group
<b>Contact/Chair</b>	<b>Czauderna, Piotr</b> Email: <a href="mailto:pczaud@amg.gda.pl">pczaud@amg.gda.pl</a> Institution: University of Gdansk, Poland	

<b>SIOPEN</b> Tumour Type: Neuroblastoma		1998
		CT group
<b>Contact/Chair</b>	<b>Ladenstein, Ruth</b> Email: <a href="mailto:ruth.ladenstein@ccri.at">ruth.ladenstein@ccri.at</a> Institution: St Anna's CCRI, Austria	