PROGRAMME ADDENDUM

Content

Printed programme

13:00 – 14:10 Tuesday June 22nd
Hall B
Special Clinical Session – Strategies for Progress
Chairs: Kate Matthay and Frank Berthold

SS2 Current and future strategies to improve outcomes in neuroblastoma: An update from the Children's Oncology Group Neuroblastoma Disease Committee Page 87
John Maris, United States

SS3 Strategies to improve outcome and quality of life in patients with neuroblastoma: Activities of the SIOP European Neuroblastoma Group Page 87
Ruth Ladenstein, Austria

SS4 Recent achievements and future strategies of GPOH to improve outcome for children with neuroblastoma Page 87
Thorsten Simon, Germany

Invited discussants

This session focuses on current and future strategies for clinical studies with special emphasis on areas of priority for international collaboration. The session intends to be interactive, chaired by two experienced experts, including three main speakers, representing three collaborative clinical groups, COG, SIOPEN and GPOH. There will be invited discussants and an active auditorium is expected.

Updated programme

13:00 – 14:15 Tuesday June 22nd
Hall B
Special Clinical Session – Strategies for Progress
Chairs: Kate Matthay and Frank Berthold

Opening

13.00-13.04	Introduction *Kate Matthay, United States and Frank Berthold, United States*	

Group Qualifications

13.04-13.16	SS2 *John Maris, United States*	Page 87
13.16-13.28	SS3 *Ruth Ladenstein, Austria*	Page 87
13.28-13.40	SS4 *Thorsten Simon, Germany*	Page 87

Challenge Round

13.40-13.45	*Michelle Haber, Australia*
13.45-13.50	*Michio Kaneko, Japan*
13.50-13.55	*Godfrey Chan, Hong Kong*
13.55-14.00	*Nai-Kong Cheung, USA*
Alt. 13.40-14.00	Invited Discussants

Finals

14.00-14.10	General discussion
14.10-14.15	Conclusions *Kate Matthay and Frank Berthold*

Page 25
Printed programme

14:30 – 16:00 Tuesday June 22nd
Room 403
ANR Nurses Special Session

Special programme for nurses in pediatric oncology and other interested.
Hosted by ANR 2010 Nurses Committee; Lisa Burström, Karin Enskär, Pernilla Pergert, Eva Turup

Updated programme
14:30 – 16:00 Tuesday June 22nd
Room 403
ANR Nurses Special Session with focus on Late-effects
Special programme for nurses in pediatric oncology and other interested.
Hosted by ANR 2010 Nurses Committee; Pernilla Pergert, Karin Enskär, Per Kogner
Chairs: Karin Enskär and Pernilla Pergert

14:30	**SS5 A national education for nurses in pediatric oncology care in Sweden** *Enskär Karin, Sweden*	see below
14:45	**POC18 Illness experience and factors that constitute resilience in families with a neuroblastoma child** *Lee Ya-Ling, Taiwan*	Page 205
14:50	**POC19 The impact of a multidisciplinary team approach in the case management of neuroblastoma** *Liu Yen-Lin, Taiwan*	Page 205
14:55	**POC22 Role of nursing in the implementation of chimeric anti-GD2 antibody with immunotherapy (ANBL0032) into clinical practice** *Mills Denise, Canada*	Page 206
15:00	**C10 Late outcomes after treatment for neuroblastoma** *Diller Lisa, United States*	Page 80
15:10	**PL36 Long-term toxicity in survivors of ENSG5 trial for children with highrisk neuroblastoma** *Moreno Lucas, United Kingdom*	Page 105
15:20	**PL35 Long term outcome: the price of treatment for surviving high-risk neuroblastoma** *Hero Barbara, Germany*	Page 105
15:30	**SS6 Perspectives on late outcomes of a patient, a parent and a physician** *Edgardh John, Sweden; Edgardh Ingrid, Sweden; Evans Audrey, United States*	see below
15:50	**Discussion**	

Page 60
Printed programme

13:00 – 15:30 Wednesday June 23rd
Room 403
Charities special session

Meeting's for charities representatives and other interested
Hosted by the Swedish Children's Cancer Foundation.

Updated programme
13:00 – 14:30 Wednesday June 23rd
Room 403
Charities special session with focus on palliation and grief with aspects of cultural differences
Meeting's for charities representatives and other interested
Hosted by the Swedish Children's Cancer Foundation.
Chairs: Olle Björk and Margareta af Sandeberg

13:00	**Welcome, an introduction to the session by the secretary general of the Swedish Children's Cancer Foundation** *Björk Olle, Sweden*	
13:10	**SS7 Sweden's first hospice for children** *Kumlien Catharina & Edner Ann, Sweden*	see below
13:30	**SS8 Cultural differences in pediatric oncology and palliative care** *Pergert Pernilla, Sweden*	see below
13:45	**SS9 The Bereavement Visit in pediatric oncology** *Isaac Yaniv, Israel*	see below
14:00	**SS10 Psychological morbidity in parents following the loss of their child to cancer – What can we do to help?** *Kreicbergs Ulrika, Sweden*	see below
14:15	**SS11 A Nordic cross-professional working group on ethics** *Castor Anders, Sweden*	see below
14:30	**Discussion and conclusions**	

“Errata”

Tuesday

14:30 – 16:00 Tuesday June 22nd
Hall B
Workshop 3 – Next generation seqencing techniques in neuroblastoma genomics
Organisers: Ingrid Öra and Tommy Martinsson
Chairs: Javed Khan and Tommy Martinsson

15:00 **WS19 Next-Generation Sequencing to characterize somatic alterations in neuroblastoma samples** Page 85
Olivier Delattre, France

Speaker replaced by Isabelle Janoueix-Lerosey

Thursday

08:00 – 09:00 Thursday June 24th
Hall A/B
The Road to Stockholm and Beyond 4
Chairs: Olivier Delattre and Murray Norris

Michio Kaneko and Murray Norris

13:00 – 14:30 Thursday June 24th
Hall C
Parallel session 11 – Prognostic factors and markers
Chairs: Kurkure Purna and Dominique Valteau-Couanet

Tushar Vora and Dominique Valteau-Couanet

14:30 – 16:00 Tuesday June 22nd
Hall A
Parallel session 3 – Immunotherapy
Chairs: Holger Lode and Jean Michon

Holger Lode and Alice Yu

Posters

POT68 Bi-directional regulation of the wild type of ALK in neuroblastoma: Its high expressionin stage 4s tumors and transcriptional activation by MYCN and Sp1 Page 195
Atsushi Takatori; Heggo Asmaa; Ajijur Rahman; Kamrul Hasan; Daisuke Takagi; Yasutoshi Tatsumi; Miki Ohira; Shamim Hossain; Jesmin Akter; Atsuko Nakagawa; Akira Nakagawara
Japan

POT 68 Withdrawn

Special sessions
SS1–SS5
SS1

A public web-based analysis tool and database for high throughput and clinical data of neuroblastoma: introduction to practical use of R2

Koster, Jan; van Sluis, Peter; Ora, Ingrid; Caron, Huib; Molenaar, Jan; Versteeg, Rogier
Dept. of Human Genetics, University of Amsterdam, Amsterdam, Netherlands

High throughput mRNA profiling is an efficient tool to identify expression levels for any gene in series of tumors and cell lines. Many tools have been developed for analysis of such data. However, most of them require specialist bioinformatic support or are time consuming or are not integrated in one user-friendly platform. We developed a tool for basic and
advanced analysis of such data, called R2. This web-based tool enables swift and user-friendly analyses by any nterested researcher. We have generated Affymetrix expression profiles of a series of 88 neuroblastoma tumors, as well as from a limited number of ganglioneuromas and ganglioneuroblastomas. The series is annotated for clinical and molecular parameters. R2 enables to analyse expression values for any gene, establish its prognostic value and find correlating expression patterns with other genes. It also permits global expression analysis and prognostic ordering for gene sets, which can be formed by KEGG pathways, functional groups, etc. Differentially expressed genes can efficiently be identified within annotated parameters, like age, stage, histology etc.
Any resulting gene list can be analysed for pathway or gene ontology enrichment, or be visualized in heat maps. Finally, the R2 tool and database includes Affymetrix expression profiles of over 20,000 normal and tumor samples from other tissues, grouped per tumor or tissue type. This enables quick searches for expression profiles of specific genes over a wide range of tissues. The web-based R2 analysis tool and database will be made publicly available at the ANR.

SS2

Current and future strategies to improve outcomes in neuroblastoma: An update from the Children's Oncology Group Neuroblastoma Disease Committee

John M. Maris
United States

The long-term objectives of our committee rely on continued robust specimen collection and annotation to support the discovery and validation efforts required for a personalized approach to neuroblastoma diagnosis, prognostication, treatment and surveillance. Ongoing projects focused on discovery of oncogenic drivers, detection of rare residual tumor cells and identifying genomic signatures of tumor behavior will all be highlighted at ANR2010, and will be integrated into future clinical trials. For patients with high-risk disease, the recent demonstration that passive immunotherapy with ch14.18 combined cytokines (alternating GM-CSF and IL2) to improve antibody dependant cellular cytotoxicity dramatically improves survival rates when administered shortly after myeloablative therapy (*Yu et al., NEJM in press*) will provide the new baseline for which
future studies will be compared. Ongoing clinical research is focused on further defining the toxicities associated with this regimen, and future studies will seek to further improve efficacy (e.g. hu14.18-IL2) and/or reduce toxicity. A parallel major goal is to improve the quality of induction/consolidation response to cytotoxic therapy. Major efforts include plans test the efficacy of ^{131}I-MIBG in frontline therapy in a randomized
controlled trial, and to integrate molecularly targeted agents into the current chemotherapy backbone of induction therapy. Inhibitors of ALK, IGF1R and AURKA are lead candidates at this time, but it is clear that a major obstacle is a continued paucity of validated targets. Prospective identification of cases harboring mutated ALK receptors may provide for the opportunity for individualized therapy in the next generation of studies. Finally, the overall strategy for patients with non-high-risk disease will be to continue to utilize biomarkers allowing for reduction of cytotoxic therapy
(*Baker et al., NEJM in press*). However, special emphasis on patient subsets with continued suboptimal outcomes, such as very young infants with INRG Stage MS disease, older children with Stage L2 disease and unfavorable genomic features, and the adolescents and young adults with any stage of disease, will require international cooperation and
harmonization of approaches.

Email: Maris@email.chop.edu

SS3

Strategies to improve outcome and quality of life in patients with neuroblastoma: Activities of the SIOP European Neuroblastoma Group

Ladenstein, Ruth
Austria

Becoming a legal entity has allowed the SIOPEN platform to grow beyond European Community FP5 funding when SIOPEN-R-NET research platform was created and currently 20 countries are engaged in the trial portfolio and research tasks.
The ongoing High-risk neuroblastoma trial HR-NBL1/SIOPEN is recruiting well and has now reached a total of 1424 patients. The first randomisation within this study has shown an important role for G-CSF during Rapid Cojec induction (Ladenstein, J Clin Oncol, in press). Recruitment for the high dose therapy question will be closed within a year having accrued 566 randomised patients so far. The recent results of the COG Study ANBL0032 had major implications on our immunotherapy arm and HR-NBL1/SIOPEN study was amended. It compares now the treatment with retinoic acid and antibody ch14.18/CHO versus ch14.18/CHO, RA and additional subcutaneous Interleukin 2 (Aldesleukin). The European legislation has slowed down the process to integrate all countries into active initiator driven protocols. This has also affected the access to antibody treatment in Europe. SIOPEN is presently building additional antibody studies for the relapse and refractory setting to investigate further less toxic modes of application. In addition, immunotherapy is also explored in a haploidentical stem cell transplant setting. The SIOPEN group is currently the only organisation in Europe with access to the antibody having developed ch14.18/CHO over the last 8 years on the basis of Europe-wide fund raising support.
SIOPEN is looking forward to launching two new trials in 2010: LINES (The Low and Intermediate Risk Neuroblastoma Study) as well as OMS (Cooperative Study of SIOPEN & GPOH & EPNS for Opsomyoclonus). Further Phase II studies are underway, i.e. TOTEM in cooperation with ITCC.
Having become partners within the SIOPE EC - FP7 project ENCCA (European Network for clinical research in Cancer in Children and Adolescents) we are thrilled that the project was granted by the EC which will foster further European collaborative neuroblastoma research and virtual tumour banking.
The SIOPEN Molecular Monitoring and the Bone Marrow group are focusing on the clinical significance of metastatic disease detected by QRT-PCR and quality controlled immunocytological techniques in bone marrow and peripheral blood whilst the SIOPEN Biology group has its main focus on the implementation and standardisation of mutilocus as well as pan-genomic techniques with a particular interest on the clinical relevance of segmental chromosomal aberrations. The SIOPEN Nuclear Medicine Group has its focus on scoring the high risk population.
The SIOPEN Surgical Committee has helped to provide image defined risk factors which have found a wide implication within INRG criteria.
SIOPEN seeks further international cooperation for specific prognostic subsets allowing to create enlarged clinical and research platforms with harmonised approaches and able to recruit a sufficiently large number of patients on trials.

SS4

Recent achievements and future strategies of GPOH to improve outcome for children with neuroblastoma

Simon, Thorsten
Germany

A key achievement of the GPOH trials is the inclusion of 99% of all national neuroblastoma cases into GPOH trials. Standards for tumor tissue collection and transport have been developed. Tumor tissue samples of all patients are stored in the central tumor repository and are distributed to reference and research laboratories. This enables the assessment of tumor tissue with various high throughput methods as RNA expression arrays and CGH. Results of these analyses provide the basis for improved risk prediction (Oberthur A et al., JCO 2006). Therefore, an increasing number of patients is expected to be identified as low risk patients. These patients will undergo treatment reduction or even observation of spontaneous regression as already shown in infants with localized neuroblastoma (Hero B et al., JCO 2008). In high-risk patients, previous trials demonstrated superiority of high-dose chemotherapy with autologous stem cell transplantation compared to oral maintenance chemotherapy (Berthold F et al., Lancet Oncol 2005), long term benefit of antibody based continuation therapy with anti-GD2-antibody ch14.18, and efficacy of topotecan based chemotherapy (Simon T et al., J Cancer Res Clin Oncol. 2007). The ongoing randomized phase 3 trial compares topotecan containing induction chemotherapy to standard induction chemotherapy in primary neuroblastoma. For relapsed patients, several phase 2 trials are open or will be opened soon. Future trials on primary high-risk neuroblastoma will focus on re-introduction of anti-GD2-antibody immunotherapy, targeted therapies on targets identified by analysis of expression data, and reduction of late effects. Small patient subsets, e.g. patients with localized tumors with unfavorable risk profile require international cooperation.

Nurses programme

SS5

A National education for nurses in pediatric oncology in Sweden

Enskär, Karin[1] ,Olle Björk[2], Ildiko Marky[3], Kirsti Pekkanen[3], Pernilla Pergert[2]
[1] Department of Nursing Science, School of Health Science, Jönköping University, [2] Childhood Cancer Research Unit, Department of Women's and Children's Health, Karolinska Institutet, Stockholm, [3] Department of Pediatric Oncology, Queen Silvia Children´s Hospital, Göteborg, Sweden

A new, advanced education in Pediatric Oncology Nursing Care for nurses in Sweden has been carried out, in three educational programs, during 2002-2010. The education was a joint venture between the University of Gothenburg, Sweden and The Swedish Children´ s Cancer Foundation who finance part of the education. The goal of this education was twofold: to bring about a broader knowledge in child oncology and nursing and lay a ground for future research for nurse in Nursing Science in Pediatric Oncology Care. Based on the criteria to admit nurses from Sweden's six Child Oncology Centra as well as from county hospitals caring for children with cancers 62 nurses were selected.

Each two-year program comprised two parts: Nursing Science in Pediatric Oncology Care (30 ECTS credits) and Medical pediatric oncology (15 ECTS credits). Between intensive educational periods of four 5 day blocks each, the students completed clinical practice and individual and group assignments. The intensive blocks included lectures, discussions and workshops in groups. The examination comprised written exams, independent essays and oral tests as well as developing an Standardized nursing care program related to a specific diagnose such as Neuroblastoma.

The evaluation shows that the education answered to the need and expectations of the participating nurses. They also felt privileged to have had the opportunity to increase their knowledge. The increased knowledge gave the nurses a higher security in their nursing role based on a broader knowledge in pediatric oncology and a greater awareness of the varying needs of the patients´ and their families. It is important in the future to offer nurses opportunity to advanced education in order to enable them to further their skills in pediatric nursing care and allow them to take part in research.

SS6

Perspective on late effects of a patient and parent

Ingrid Edgardh and John Edgardh, Sollentuna, Sweden

Four years old John was diagnosed with high-risk neuroblastoma stage 4 with his primary tumour in the adrenal, bone metastases in the skull and tumour cells in the bone marrow. At presentation he had suddenly started to squint. He had elevated intracranial pressure due skull metastases and thrombosis. John was treated with OPEC/OJEC chemotherapy, surgery, radiotherapy to the abdomen during surgery and to the skull metastases, high-dose chemotherapy with stemcell rescue and treatment with 13-cis retinoic acid.

Today John is 18 years old. He seems to be free from the neuroblastoma but his daily life is affected by late effects of the disease and treatments. John is smart and humoristic; today he is a strong and colourful person. He has payed a prize of treatment for surviving high risk neuroblastoma. In the seminar John will for the first time in public tell about his perspectives of being a survivor.

When John started to recover after the treatments his difficulties slowly became obvious although his first years was clouded by the fear for relapse. Meanwhile John and his family struggled with his severe difficulties to concentrate and to remember, his ticing, an enormous fatigue, pains in his legs and stomach and difficulties in school. The family all had to learn what it meant to live with hidden disabilities and the demands it made on the family. His parents have had a very long struggle to get proper support for John and to find a school with pedagogical skills. The knowledge of how to support a child with a different brain function caused by neuroblastoma and its treatment is lacking.

The last 13 years has taught me, his mother, to live on the thin line between hope and despair. It has taken our family to places with different views of the landscape of life. Some of them have had a painful beauty, some has just been too heavy, and there have been moments of overwhelming luck. During these years we have learned the importance of transforming the meaningless to something constructive and enjoy our lives. Most important we have had the luck to see John and his two siblings growing in midst of our family.

An extract from the book *Can I Die, Mummy?* (Kan jag dö, mamma? Alfabeta, 2005, translation by Sarah Death) written as an attempt to explain what cancer can do in a family:

"One day, death came to visit. He didn't bother to ring the bell, just walked straight in, pulled out a kitchen chair and took a seat. As if that was okay."

I had dreamt of a big, happy family. A world where the nasturtiums trailed and the cat sat on the steps, purring. Then we got the news: our John had one of the most incurable forms of child cancer. One in ten survives. The illness didn't ask our permission and death became an uninvited guest at our dinner table.

There was no cat purring on the steps. The nasturtiums grew, but nobody tended them."

Ingrid Edgardh is mother of a child with neuroblastoma. She is an ordained priest in the Church of Sweden. She has become an asked for lecturer talking about the experiences of having a sick child and her reflections, believes and thoughts about parenthood and sickness.

Charities Special Session

SS7

The first Hospice for Children and Youth in Sweden

Ann Edner
Stockholm, Sweden.

In September 2010 the first hospice for children and youth will open in Sweden. It has been a lot of prework done making this possible. Looking outside Sweden the world´s first hospice for children and youth opened in Oxfordshire, UK, in November 1982 and shortly thereafter the United States got the same.
Children´s hospice care focuses on life and living. Providing hospice services for children and youth with life- threatening conditions and their families presents an uniquely difficult and rewarding task. One of the challenges faced is that many pediatric referrals come to hospice very late. Parents need the support of hospice care services, but are not willing to give up on aggressive therapies for their child/youth.
The first Swedish Hospice for Children and Youth will be placed at Erstagården south of Stockholm and have the capacity to take care of 7 children with their families. It will be open for incurable, progressive sickness, but also for irreversible non-progressive sickness where the parents need to be relieved pressure. Preferably patients from the Stockholm area will be referred to the Children´s Hospice, but it will also be possible to send patients from outside Stockholm.
The palliative care will include medical personnel (nurses, doctor), physiotherapist, occupational therapist, psychologist, care for the soul/spirit. We also think that complementary treatment is very important, for example we will introduce the first therapy dog in pediatric care. She is a labradoodle called ”Livia”.

SS8

Cultural differences in paediatric oncology and palliative care

Pernilla Pergert[1], Solvig Ekblad[2], Karin Enskär[3] and Olle Björk[1]
[1]Dept. of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden. [2] Dept. of LIME, Karolinska Institutet, Stockholm, Sweden. [3]Dept. of Nursing Science, School of Health Sciences, Jönköping University, Jönköping, Sweden.

Paediatric cancer, including Neuroblastoma, often entails demanding treatment and a long period of cumulative stress for the entire family. Furthermore, Sweden has become an increasingly multicultural society, resulting in a need for studies in transcultural care. The aim of these studies was to gain knowledge about healthcare staff's experiences of caring for families with a foreign background within the context of paediatric oncology. Grounded theory methodology was used. Five focus group interviews were performed with healthcare staff and twelve individual interviews were performed with nurses with experience of caring for families with a foreign background from different areas of paediatric care including end-of-life oncological care. Obstacles to transcultural caring relationships includes: linguistic, cultural and religious, social, and organizational obstacles. Cultural and religious obstacles have several potential consequences that are of outmost importance in end-of life care including; differences in truth-telling and differences in emotional expressions. Differences in truth-telling concerns different views and practices regarding conveying sensitive information to the patient and can differ between individuals and cultures. Truth-telling differences can cause genuine ethical dilemmas in care. Furthermore, differences in emotional expressions in transcultural care, including overwhelming emotional expressions of wailing, have been found to override nurses' professional preparedness. This further has consequences for views on the good death. Strategies for bridging cultural and religious obstacles, including strategies for protecting professional composure, will be presented and discussed. The present studies stress the need for culturally awareness and competence in order to provide culturally congruent pediatric oncological and end-of-life care.

SS9

The Bereavement Visit in Pediatric Oncology

Isaac Yaniv
Pediatric Hematology Oncology Schneider Children's Medical Center of Israel, Sackler Faculty of Medicine Tel Aviv University, Israel

Among the many traumas that assault the family of the child who dies of cancer is the sudden detachment from the staff of the oncology unit after a long period of close collaboration. A child's last days are often characterized by intense palliative efforts and emotionally charged interactions between the staff and the patient's family, which stands in contrast to the go-it-alone vacuum of the empty and lonely time in which the family now must find their way. Detachment from the oncology unit is added to the long list of decathexic tasks that the family must perform as part of their work of grieving. Conversely, oncology staff members also deal with disengagement from the bereaved family and the dead child; sublimation of this process into the hectic daily routine of the ward can lead to unresolved emotional needs surrounding the issues of death and mourning and, possibly, to the burn out so often encountered in those who work with children with cancer.

A bereavement visit by the oncology staff is a way of filling this void. It may also facilitate the early phases of mourning for the family and give the staff profound insight into the tragic drama in which they had recently participated.

Our staff has performed home bereavement visits for more than 20 years. Families have come to expect these visits, and they have become as much an integral part of our end-of-life care program as the administration of analgesic medications. Every family is visited, even if they live far from our facility. These home visits are part of an integrated program that we provide for bereaved families that includes a condolence letter by the department chair, small support groups for parents and siblings during the first year after the child's death, and larger meetings of bereaved parents for formal lectures and informal discussions. The visit team includes the child's primary physician, a nurse to whom the patient was particularly close, and the family's social worker.

Various aspects of the bereavement visit, including difficulties encountered, will be presented based on our experience.

SS10

Psychological morbidity in parents following the loss of their child to cancer – what can we do to help?

Ulrika Kreicbergs
Karolinska institutet, Stockholm, Sweden

The loss of a child is described as one of the most stressful life events possible. The grief following the loss of a child is more intense and longer lasting than any other losses. Bereaved parents are at increased risk of psychological morbidity. Yet, no time frame has been established. Some studies suggest it might take about four to six years to work through the loss of a child. Even though it a traumatic experience most parents come to terms with the loss over time. Before the loss, caused by illness, parents are commonly exposed to protracted physical and emotional suffering of the child. A number of factors may impact the bereavement outcome e.g. other losses, financial problems, pre morbidity, all factors that cannot be managed or avoided within the health care setting. Even the age and gender of the child has been found to affect parental bereavement outcome. For fathers the risk of anxiety and depression is greater after the loss of an older child, i.e. above the age of eight. Their risk of anxiety and depression is nearly twice as high compared to fathers losing a younger child. No such risk related to the child's age is seen in mothers. In addition to the age, gender of the child affects mothers and fathers differently. None of these risk factors can be managed or avoided in health care. Still, it may be of importance for clinicians to aware of them in their daily work with families.

Some factors are modifiable or even avoidable in the health care. The child's suffering e.g. from unrelieved pain is known to affect bereaved parents. Not having clinicians present at the moment of death increases parents likelihood of reporting unrelieved pain and also a difficult moment of death. Location of the child's death is another factor demonstrated to impact bereaved parents morbidity. Fathers are less likely to suffer from depression if the child dies at home. Yet, it may be questioned whether it is the actual location of the child's death that is of importance or the planning of it that is important. The latter leads us to the significance of communication in paediatric palliative care and parental bereavement.

In pediatric palliative care communication is possibly of the same importance as the knife in surgery. Open and honest communication has been emphasized. However, to inform families when care shifts from curative to palliative is a challenging task. Clinicians should offer parents special support during this time. It has been found that support to parents as late as during the child's last month improves their grieving process. Communication about the child's prognosis has proven valuable for the bereavement outcome. Most parents want to be fully informed, yet clinicians fear this type of communication. Parents who have been informed by clinicians that their child's death is imminent are, not surprisingly, more likely to be aware of the pending death. Parental awareness impacts a number of factors e.g. tailoring the child's care according to their wishes. Home care and even home deaths is more likely to be considered if parents are aware of their child's death being imminent. Parents being aware of the child's imminent death are more likely to talk about death with their child. Such an approach has been shown to reduce the risk of psychological morbidity in bereaved parents. If the parents perceive the child to be aware of his or her imminent death this is the strongest predictor of actually talking to the child about death. Many children in paediatric palliative care are unable of any type of communication because of age, birth defects or illness. When the child is unable to communicate mothers are more likely to think that it would be best for the child to die. This does not apply to fathers; they are less concerned about lack of communication.

Assisting grieving families is an important part of pediatric palliative care. It should start already at the time of the child's diagnosis. Bereavement support has been studied but with conflicting results. Several studies have shown both professional and social support to be beneficial for parents' grief outcome, but not all parents find it helpful. Some parents want to cope on their own, with or without support from family or friends. To identify parents at risk for pathological grief reactions is a challenge for clinicians. Tailored support to those who need it most is the goal.