



## GREETINGS

### **Address by Two Mothers**

at the reception in the Residenz on November 3, 2010

My name is (...); my 13-year-old daughter has anorexia and is currently attending the clinic's school for sick children as part of her treatment with Dr. Rohde in the Paediatric Clinic Schwabing. I view the school for sick children from the perspective of the patient group anorexics and persons with psychosomatic disorders.

I would also like to introduce myself: my name is (...) and my son Elias contracted leukaemia four years ago. He is also being treated in the Paediatric Hospital in Munich-Schwabing. In view of this lifethreatening situation, I must admit that my last thoughts were about schooling. This is probably the case with many families in which children are suffering from a severe illness. I stand as a representative of these families here today.

Both: Up until a short time ago, we were not even aware that there was a school for sick children. Now we have become passionate advocates of this institution. We offer our heartfelt thanks to all those who set up and supported this institution and continue their commitment in these schools. We urge all political decision-makers to provide all necessary funding for the school for sick children, even in these times of pressure to economise. Please lend your support not only to tuition in paediatric clinics but also for all prevention, advisory and aftercare services.

We are aware that a task has been set according to the German constitution to provide compulsory education for all children, including those with health problems which will guarantee their right to a school education – this has been formulated by the Ministry for Cultural Affairs. For me and my sick child however, it is very much more. This school provides my child with a piece of normality and a distraction from poor health. It reduces anxiety, for example the fear of losing the prized and stabilising community of the child's former class. It takes away the fear of falling into a deep scholastic trough which seems insurmountable after emerging from the protective atmosphere of the treatment environment, which in itself naturally also causes new anxiety and a sense of failure.

First mother: I hope you will not misinterpret this as the outpourings of an over-ambitious mother who is relieved that her child will perhaps be able to avoid repeating a year. I – like the majority of parents in my situation – have become extremely modest and emphasise that I do not view the school for sick children as a saving mechanism against repeating a year or as a guarantee for a particular school career, but as a building block of a holistic treatment approach and a vital aid to recovering from the disease.



Second mother: I would like to join in at this point. Even in the precarious situation of children with lifethreatening diseases – a state in which everything is centred around physical stabilisation and hopefully also a successful recovery, a state in which chemotherapy and radiotherapy dates dictate the structure of each day – even then, the school for sick children is an essential element of these children's lives. There is a teacher who will return every day – irrespective of how poorly the children are feeling or how grumpy they may be on a particular day. Why does she persevere? Because she assumes that this severely sick child will sooner or later be able to return to a 'normal' life. Even in times when we – parents and children – were not certain whether recovery would be possible, this teacher was able to provide us with a feeling of security and normality. This was how the school for sick children became a 'rescue rope' for the life of my son.

First mother: Now onto the topic of prevention: anorexia or psychosomatic illnesses and behavioural disorders are on the increase. Early intervention is vital and can shorten the duration of subsequent treatment. I have experienced perplexity and helplessness, the feelings of guilt and have trodden the difficult path towards the realisation that the condition has nothing to do with adolescent flights of fancy. I subsequently found out that the teachers were either as clueless as I was or didn't have the courage to address the problem, fearing extreme reactions. In my opinion, an important role for the school for sick children within the framework of prevention would be to inform teachers and provide support for them in the case of early intervention.

Second mother: What was really helpful was to experience that the school for sick children did not consider the job to have been completed on the day of discharge from hospital. Reintegration in a normal school is not a simple matter after such a long period of absence. In the case of my son, I experienced a wide range of support and continue to do so: visits to his normal school, discussions with the school council and school psychologist, procurement of medical reports and last but not least detailed discussions in which we weighed up the pros and cons of important decisions... what I experienced here is much more than I would expect from teachers or heads of school: interpersonal warmth and honest sympathy which gave me and my family great strength and continues to do so.

First mother: There is another topic that I consider as important which has nothing to do with schools or the Ministry of Cultural Affairs, but is directed at the decision-makers within the healthcare sector. There are insufficient places for anorexia patients, particularly those who are very young, for example only 11 or 12 years old. In the Paediatric Clinic in Schwabing, there is a waiting time of between six months to one year for medical treatment. During this waiting period, the children are cared for in an acute ward or in intensive care to bring them out of a life-threatening situation, frequently on several occasions during the waiting period. As medical experts, you can easily imagine the dramatic consequences this procedure has for patients and their families. Professional experts have confirmed that this can permit the disorder to become chronic and make subsequent treatment longer and more difficult.

I work in the field of business administration. After years in any profession, everyone develops a



# 7<sup>TH</sup> HOPE CONGRESS MUNICH 2010

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deformation professionnelle, myself not excepted. For this reason, I would like to underline this point from a managerial aspect. An investment in more treatment places for patients to reduce waiting times costs money – naturally – but can also save money. Imagine how much it costs to treat a young patient several times in an acute ward or in intensive care where only the symptoms can be relieved. If it was possible to shorten or even eradicate this process, additional investments would pay for themselves.

Back to the topic of the school for sick children: the combination of medicine and education has been of great help for both parents and their children. We wish doctors and teachers great success and hope that many young patients receive this support which was of such great value to us.

We also wish this congress every success.