

**Editors  
of this number****Hope Board**

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## Teaching sibling at the hospital school

A sibling implies joy. However, the happiness can be transformed if a brother or a sister gets a severe disease. The daily live for the entire families change when a son or daughter gets treatment at the hospital. It's a difficult situation for everyone to find their daily routines. Siblings, who grow up together, have both emotional and social cohesion, which makes the time hard for both of them. Research has demonstrated that siblings of severe sick children may have significant emotional and behaviour changes<sup>1</sup>. If the siblings are of school age, it's important for them to continue their tuition and lifelong learning within their home schools or at the hospital school, where their brother or sister receives medication. Olga Lizasoáin, University of Navarra (Spain) works for introduce American Child Life programs which help the entire family to better cope the situation of childhood disease and support brothers and sisters. You may write to [olizas@unav.es](mailto:olizas@unav.es) for additional information. Results of research show that the ambient treatment with support sibling tuition and their spare time may have significant impacted children's' health care and their learning ability <sup>2</sup>. The school system of every country has the responsibility to ensure that all children receive tuition according to The UN Convention on the Rights of the Child date 1989. Márta László, Hungary writes that all children may get tuition, when families live a longer time in Déméter-house, Budapest. Children's Cancer Association in Sweden has engaged a sibling support at the three largest children hospitals to reduce the siblings' stressful situation.

*Agneta Grunditz Board of HOPE*

- 1 Dev, J. (2007) *Pediatr* 28:1-1 <http://pediatrics.aappublications.org/>  
 2 Passer, M. Smidt, R. , Holt, N., Bremer, A., Sutherland, E. and Vliek, M. (2009) *Psychology The science of Mind and Behaviour*, McGraw-Hill Companies (UK)

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Clip courtesy of AGESO

## Schools in Hospital

### My work as a Sibling supporter

The sibling plays an important role for the sick child's recovery and stand for security, friendship and support. However, the siblings of our patients have their own complex set of needs and require much more support than it is recognized. The Sibling Project started in 1999 at the Department of Pediatric Oncology and Bone Marrow Transplantation in Lund to provide appropriate help and support to the entire family, and in particular, the siblings affected by life threatening disease of one of the family member. The project is financed by Children's Cancer Association in The South Region. The sibling caregiver emphasizes the child's need of individual support. Another part of the work is to offer the sibling participation in a meeting group or in a network consisting of other siblings. Also the siblings who's lost there sick siblings, is important to have a contact with, as long as the sibling has its needs. What we usually do in groups is varies, sometimes we go bowling, to see a movie, goes swimming, or camping. The sibling supporter also offers information in the siblings' school class or daycare. It is of importance to remember the siblings "usual life". The purpose is to make the siblings participate in the care of the sick child and hereby increase the comprehension. The sibling supporter is the sibling's advocate/attorney. She always gives her full attention to what's best for the sibling and place the sibling in focus.

An important part is to inform the siblings about the sick child's diagnosis and treatment. The caregiver always asks the sibling how much they know about their sick sibling's disease and treatment.

Material is used during the talk to explain. It is important for the healthy sibling to have available resources for help. Offering the siblings a sibling supporter on the ward is crucial for well being of the entire family. The sibling relationship is a unique bond shared between two individuals. It's a union that did not begin voluntarily, but is supposed to last a lifetime.

Petra Svensson, Lund, Sweden

*It is important  
to remember  
the siblings  
"usual life"*



## Pupils with and without medical needs in the hospital school

Karin was twelve when her little sister Maria, eight, was diagnosed with an osteosarcoma. For Karin it meant to learn to handle the severe shock and the fear while at the same time life had to continue. Her parents took turns staying with her sister. Karin all of a sudden saw herself as a stand-in for her mother and father at home. Their friends and colleagues called to ask about her sister and her parents. She became the family's information centre. Nobody asked how she was doing. She was told how important it was for her and the family that she was strong and helpful. And she was. She turned into "super sister". She answered all the phone calls and she continued her school work. The family lived close to the hospital and so Karin too visited her sister daily but never invited to take part of information nor offered counseling as were her parents. Her teachers did not ask any questions about how things worked out at home. She was expected to do her school work as usual.


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She turned into  
"super sister",  
but *nobody*  
asked how she  
was doing


Looking back she feels both angry and sad. Karin and other siblings to patients undergoing treatments for a cancer started a discussion group. During these meetings they could talk about the experience they have in common. They shared feelings of not having wanted to admit neither to themselves nor the parents or anyone else that they too needed support. They couldn't bring themselves to ask for anything on their own behalf. How they were there but not included. Even if they would have wanted to know more they wouldn't have liked to be present every time information was given to the parents. But at least they would have appreciated being asked. The group suggests they'd be given an envelope with a letter telling them of their right to be kept informed and a few telephone numbers to a doctor, a psychologist or a social worker. This will make them feel included while at the same time it is their decision as to what extent they want to use this offer. As it were they were left alone with their feelings of anxiety and guilt for not doing what they felt was expected of them from parents and people around and at risk of feeling lost, abandoned or a nuisance. Karin did not go to our school in hospital, though today I think she would sometimes have used the possibility to at least have a calm place where she could sit and study without having to rush home to do her homework. Karin's sister fell ill in 1992. We had not yet started our visits to the mainstream schools. Today a consulting nurse and a hospital teacher will visit all schools where there is a pupil with a cancer diagnose. These visits follow the common pattern of informing about the illness, the treatment and setting up plans for home education; generally future collaboration mainstream school – hospital school. These visits will include information in a sibling's class as well. As a rule tuition in the hospital school is offered to siblings. For how long depends on background circumstances. Sweden is a country where you often have to travel far

for specialized treatments. At least one parent is always expected to be with their child in hospital. Sometimes both parents are needed for the sick child in the hospital or it is the case of a single parent. Sometimes there is no social network back home that can step in and offer support. Spending a few days in the hospital helps to lift off worries for a sister or brother. Knowing what things are like is so much better than being left alone with one's own imagination. Instead of sharing the extra bed(s) in their room in hospital with the parents, teenagers sometimes wish to invite friends or a boyfriend/girlfriend with them for a few days. As teachers we appreciate having siblings and friends in the classroom and so do our patients/pupils because it enables them to interact in an extended group. They add a bit of "normalcy" to the hospital environment which is one of the reasons to be of the hospital school. In our school we also offer educational care to children of parents where one partner suffers from a terminal or serious disease which requires a longer stay in

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*As teachers we  
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classroom.*




hospital and they are a long way from home. Sometimes our pupils are newly arrived immigrants. If possible we teach Swedish as a subject to the parent as well so as not to make them miss their Swedish class at home and cause a break in their process of integration. These "external" students don't require much extra work. They bring their own books and have plans ready sent by their own teachers at home. They work according to a daily schedule along with our pupils that are admitted to hospital, they participate in the same outdoor activities and excursions as they do and of course spend time together with them in the play therapy. Finally it has to be noted that these students do not even exceed 1 % of the pupils in the hospital school during one academic year.


Gerd Falk-Schalk , Uppsala, Sweden

## Education and hospital treatment of siblings Children's Tuberculosis Hospitals of Lithuania

Quite often, in Children's Tuberculosis Hospitals, treated and taught are children from the same families. Usually, when a child gets sick with TB, his/her brothers' and sisters' medical checks are conducted too and they are hospitalised if necessary. Given that in most cases the risk to be ill with TB is higher in deprived families, treated in hospital are often brother and sisters. However, it is not a rule: brothers and sisters from well-to-do families contract TB too. According to doctors of Children's Tuberculosis Hospitals, many efforts are being made to create appropriate conditions for keeping children from the same families together. Little patients (brothers and sisters) are usually placed in the same wards, whereas the older ones are put separately, according to their gender. In those cases where brothers' and sisters' age differs substantially, children are distributed into different wards: but they do not worry about that since they can enjoy each other's company quite frequently. In addition, children of different age are being put in the same ward too, provided they can enjoy comfortable privacy and wish so. For example, last year sixteen-year-old and five-year-old sisters were being treated in the same ward. Currently, there are two sisters hospitalized in the same ward. Regarding organization of children's education, children of different age are usually taught separately. However, if a child is very young, he is allowed in the beginning (in rare cases) to be at lessons together with his elder brother, during which he is usually busy with certain task given by the teacher so that not to disturb the others. However, given that elder sisters and brother often get tired of taking care of their little ones, efforts are put to provide quiet teaching conditions, thus leaving the little ones in the nurses' and housemothers' care. In those cases where brothers and sisters are in the same grade they are taught together.



*Brothers and  
sisters are  
often treated  
together*



*Genovaite Petrauskiene  
Headmistress of Vilnius J.Lauzikas comprehensive consulting centre*

## Being brothers and sisters of...

### *Outside the Hospital*

Having a sibling with severe disabilities is a common condition in a large percentage of the population, and by no means a "comfortable" one. According to scientific literature, siblings of disabled people must face significant issues in the building of character and personal balance that "normal" people of the same age don't have to deal with: working through the sense of shame, feeling the pressure to be always "adequate" (the healthy sibling must avoid causing trouble - there's enough already!), a sense of hyper-protectiveness toward their parents, fear of death and disease... such issues concern more or less deeply all these boys and girls and can turn out to be either great opportunities to mature, or burdens that negatively affect their future lives and choices. Despite these facts, actual and practical initiatives involving the siblings of disabled people are few and far between: there's a lot of talking about disability, but it's impossible to take care of everything ("there's so much to do for the disabled people anyway").

This challenge was taken up by Ring14, an international Association located in Reggio Emilia (Italy) and committed to the support of scientific research on a rare and unknown disease related to Chromosome 14. In 2009 Ring14 devised a pilot project by collecting twelve preadolescent boys/girls who had siblings with various disabilities and backgrounds. Key words: being happy together, having the chance to commune with other children who understand what it means to have a disabled sibling. This project produced a wonderful group that kept walking down the same road for a year, spending nights and days joined by the red thread of participation and of joyful cohesion and culminating in a grand summer adventure - setting sail on an Italian navy brigantine ([www.tendertonaveitalia.it](http://www.tendertonaveitalia.it)). After this experience was over, it became clear that it couldn't really be ended this way: the children were

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expecting - even demanding - to carry on with the project, and their families - an unforeseen but valued outcome - had spontaneously formed a parallel group, taking advantage of the children's activities to create their own opportunities to meet and have fun. In 2010, Ring14 opened the project to new boys/girls (twenty participants) and raised the challenge complexity: during the near-monthly meetings the "field team" - composed of a psychologist and two educators - laid emphasis on the "psycho educational" approach, discussing "hot" topics in a playful way and through the help of the shared summer experiences, including the sailing and a camping holiday. The field team was complemented with two professional psychologists, expert in family dynamics, who guided the parents' group along a path of mutual comparison and growth.

In conclusion, facing the subject of disability isn't just dealing with the problems of a single person, but with the hardships of a whole family: helping any one of its members means triggering a potentially favourable change that will benefit the entire family. This is the fundamental insight that inspires and guides the project "Being brothers and sisters of...".

For additional information:

Ring14 ONLUS, Italy; [www.ring14.it](http://www.ring14.it) Tel: +39 0522 421 037 E mail: [info@ring14.it](mailto:info@ring14.it)





*Let's get together*

## Open the box: Seeking for Comenius partners

The Alava Hospital School from Finland is seeking for two to four partner schools to start a joint Comenius project. The school is open to discuss and define the main topic of the project among the partners. It wishes to connect the Comenius project to the school development activities and thus is interested in the following themes.

### 1. **Hospital school as resource centre**

Education policy as well as health care is changing rapidly at the moment, which might influence the roles and responsibilities of the hospital schools and of the mainstream schools. Due to increasing inclusive education, pupils study more often in mainstream schools instead of hospital or special schools. Therefore the role of the hospital schools might change a bit towards the resource centre in the future.

Possible subthemes could be:

- Consultative work
- Improvement of multidisciplinary collaboration
- Working methods and tools to support mainstream schools

### 2. **Prevention of exclusion / drop-out**

According the latest researches, special needs students drop-out rate from primary and secondary education is higher than other students. Young adults without adequate education might have difficulties to enter to labour market which can lead to the marginalisation. Also hospitalized pupils might have severe difficulties with their studies which can increase their risk to drop out.

Possible subthemes could be for example:

- Role of the Hospital School in prevention of marginalisation

the School wishes to have your replies and proposals till the end of April 2011.

If at least three partner schools will be interested Alava school is willing to organise preparatory meeting in Finland

Please, do not hesitate to ask further questions or clarifications. In order to get some more information about the school, you will find PowerPoint presentation on <http://www.peda.net/veraja/kuopio/alava>

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## Inaugural Australasian H.E.L.P. Conference

Our Australasian colleagues are pleased to announce that registration is now open for the Inaugural Australasian H.E.L.P. Conference: Health, Educators, Learners and Practitioners to be held the 5-6 September 2011, Coogee Beach, Sydney Australia.

The 2011 H.E.L.P. Conference is proudly sponsored by Ronald McDonald House Charities in collaboration with Hospital Schools in Australasia and the University of Technology Sydney.

The conference will provide the opportunity to highlight the importance of integrated service provision, research, innovative practice and cutting edge professional development strategies for children with chronic health conditions.

Get in early to register for the special Early Bird rate!

<http://www.cievents.com.au/events/HELPConference2011>



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