

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

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CALL FOR PAPERS

Outdoor education and sport

Learning and practicing to an independent life with positive self-feeling¹ is the most important point for many children with chronic disease or disability. The school has to support these children's cognitive and physical development as far as possible according to Unicef - the Convention on the Rights of the Child, Articles 6 and 29².

In most European countries, children with disabilities and chronic diseases can be offered to participate in camp activities and cultural experiences by various associations and foundations. Many children's hospitals and hospital schools are working together to arrange such trips and camps during summer and winter. Physical outdoor activities seem to convey a calming effect on the mental health and make it easier for individuals to handle stressful situations while experiencing in the nature may also stimulate children's creative and social development.

- Play in outdoor environments has been shown to affect children's health positively, both mentally and physically. Outdoors activities and be able to play can have children to make them less stressed. It is also important for their development to do things that children normally do, even though they are in hospital, said professor Ulrika Stigsdotter³.

Visiting and participating to cultural events, meeting famous people inside or outside the hospital develops and increases children's ability to become a grown up person.

1 AAIDD (2010) Intellectual Disabilities: Definition, Classification, and Systems of Supports (11th Edition). Washington, DC: American Association of Intellectual and Developmental Disabilities

2 <http://www.unicef.org/photoessays/30048.html>

3 [http://curis.ku.dk/portal-life/da/publications/konceptmodel-terapihaven-nacadia\(48d08620-bd58-11dd-8e02-000ea68e967b\).html](http://curis.ku.dk/portal-life/da/publications/konceptmodel-terapihaven-nacadia(48d08620-bd58-11dd-8e02-000ea68e967b).html)

Edited by

the Board



Camp For Children And Adolescents with end-Stage Renal Failure

In the Paediatric Dialysis and Transplantation Centre of the Paediatric Nephrology Department in Ljubljana, Slovenia fifteen children and adolescents are currently on haemodialysis and peritoneal dialysis. They long for the annual three-day camp that is one of the most significant aims of the Hospital School. All children can participate in that Camp even if these patients with chronic kidney disease usually spend most of the time between hospital walls. They cannot spend a long holidays on seaside swimming or snow-covered hills skiing. They are submitted to a special life rhythm so our camps break theirs uniformity for three days.

Every year we choose different place, when and where, the camp will be. Our team of doctors, nurses and teachers, try to raise funds for realization of the Camp, because the Camp is free of charge for participants. All the volunteers are from our department or from other organisations or students.

The Camp runs the whole time together with cooperation of all participators; children, adolescents, parents of younger children, medical staff (doctors and nurses), psychologists, school teachers and guests like scouts, divers, cooks, dancers, hairdressers, photographers, skydivers, musicians. We are all equivalent members of the Camp and we all contribute that our time together will be of the best quality. All things together develop a good health, competitive spirit, knowledge, sense of tolerance, loyalty and understanding each other, stimulate of positive self-image, create a relax atmosphere outside the hospital walls.

The camps are very popular and exciting event for all of our patients.

Sinja Jančar, math teacher, hospital teacher

Hospital School Ledina Ljubljana, Komenskega 19, 1000 Ljubljana



*positive self-
image, a
relaxed
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outside the
hospital walls.*

Grieving process training



We have started this school year with a very interesting and useful training at the Hungarian Hospital Teacher's Association. Dora Monostori, mental health professional and grief consultant, and our colleague from Szeged held a two-days training in Pécs. Professionals in education from all over the country participated in the training, and during these two days they spent their time not with their usual supportive tasks given by their role. Instead they had the opportunity to talk about their own grief and unprocessed bereavement. It became clear that there are not any exact rules how to process grief but it is easier to overcome it with support of a professional, even in the most painful moments, to process the loss of our beloved pupils.

At the end of the training session all participants received The Grief Recovery Handbook written by John W. James and Russel Friedman which I would like to recommend to all hospital teachers. Look at the bookshop <http://www.griefrecoverymethod.com/books/>

Marta Laszlo, Hospital Teacher, Committee member from Hungary
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From the Board: *The HOPE Board gathered for a scheduled meeting on March 22nd in Leuven, Belgium. The day of our arrival in Leuven coincided with the funeral of the schoolchildren who died tragically in the fatal bus crash in Switzerland.*

Mary McCarron, Board Secretary, representing the Hospital Teachers of Europe, joined in solidarity with the local people and attended the funeral. She also left a card on behalf of HOPE, sympathising with the parents/guardians, families & friends on their terrible loss.

A Competence Centre for Rare Diseases in Sweden

National Competence Centre for Rare Diseases, Ågrenska, Göteborg, Sweden

Since 1989 Ågrenska has arranged about 20 camps annually for families who have children and adolescents with rare diseases. Rare diseases are syndromes, that are have different symptoms, and lead to multifunctional needs which change during the child's grown up.

Read more at National Association for Rare Diseases

http://www.sallsyntadiagnoser.se/In_English

Functional limits are rare and not always the knowledge of these diseases are known in schools and health care. The rare diseases may sometimes lead to specific difficulties at the school. Teachers and classmates are not always nice to these children because they don't really understand them. Parents have reported that they have to fight for the children's' right to get resource and the special need in education and despite they are not believed. The National Association for rare Diseases reports that about fifth part of the parents who asked for special need in education never got any help from the children's school.

At the camps the children and their families will meet other participants in the same situation. The children learn more about understanding each other, their situation in the society and stimulate their positive self-image. They also enhance the children's fitness and strengthening their health in a very beautiful area closed by the beach. The participants may play or have physical training in the garden or in the beach.

Each child and adolescent get an own program which trains them in teaching and in leisure activities. The programs are individual and pedagogical arranged in small groups with a lot of professional staff.

The siblings offered opportunities to share experiences on how it's to have a sibling with rare diseases. The siblings may meet each other in small groups if they wish.

The camp at Ågrenska uses to be very popular and the children with rare diseases and their families long for the annually camp in the relaxing, healthy area.

Teachers and classmates are not always nice to these children because they don't really understand them.

Pupils of the Kannerklinik visiting Grand Ducal Palace

For children with chronic diseases, this type of experience is an important resource

Since the beginning of school year 2009-2010, Luxembourg has its first hospital school for sick children at Kannerklinik, the Pediatric Clinic of the Center Hospital in Luxembourg City.

In previous years, there was already school offers, but the signing of a cooperation agreement between the Ministry of Education and the Centre Hospital of Luxembourg has made it possible to enter a new stage in the care of sick children. Four teachers are now involved in pediatric and child psychiatry, to teach children.

There are very few moments when all the children can gather because the school time table must be adapted to each individual's care. Despite all the difficulties related to the organization we were able to gather 16 children, with their doctors, nurses, hospital teachers and other medical staff to visit the Grand Ducal Palace at the invitation of the Grand Duchess Maria Teresa , May 23th, 2011. After a solemn arrival of the delegation to the palace's official entrance, the Great Duchess personally welcomed the children to introduce them to the scene. She took her time to explain to the young visitors the use of each different room and the role the Palace has played in the history of the country. The children asked many questions to the Great Duchess and the exchange continued during the lunch offered to the group in the Balance Hall after their visit.

The visit at the Great Ducal Palace was a wonderful experience for all participant. To gather children, hospital teachers, doctors, nurses and the staff for a same activity outside school and outside the hospital creates a special dynamic and favors exchanges that are not possible in everyday life.

For children with chronic diseases, this type of experience is an important resource. For hospitalized children in child psychiatry this adds to a very important message: You are welcome! Faced with a society that often tends to isolate, from an early age, people with a psychological illness, the invitation of the Grand Duchess was an important symbolic gesture of inclusion.

Bob Kirsch, Luxembourg, bob.kirsch@education.lu



The Nave Italia brigantine and foundation



Nave Italia is a magnificent sailing vessel, the largest brigantine in navigation. It belongs to Tender to Nave Italia Foundation whose aim is to develop national and international projects recommended by non-profit organizations. The founders are the Italian Navy and Yacht Club Italiano. Tender to Nave Italia sails, hosts and enhances groups of people while teaching solidarity through the sailing experience and the natural rules of the sea.

The foundation uses sailing to fight the social apartheid of the disadvantaged. Its tools are cooperation and integration among the composite sailing crew. Aboard Nave Italia people work in teams; together, goals are reached and even those which seem impossible are achieved.

Any non-profit organization, school or institution can present a project in order to access to the foundational resources. Nave Italia is the main available tool, the 61 meter-long brigantine which can host up to 24 people plus the crew, which also includes one professional educator. Every project presented by non-profit organizations, schools or institutions, is assessed by a committee. In order to be approved it has to aim to overtake social apartheid and prejudice against the disadvantaged and to present out-of-the-box ideas.



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Next Hope conference – Call for papers

8th HOPE-congress, Amsterdam, 9-13/10/2012.

Topics: Approaches to education in changed treatment of illnesses and medication - Changes in multidisciplinary approaches to education during hospital admittance and afterwards - Changes to necessary new competences of the hospital-teacher - Good-practices and experiences with "teaching the hospital-teacher" Changes in educational and social relationships with sick children, their parents and their home schools - Ensuring continuity in education of chronically ill children and adolescents - Career orientation support and assisting the transition to employment - Active aging with a somatic or psychiatric illness - Hospital-teaching and the use of social-media - Examples of good-practices in the daily-work of a hospital teacher - social developments that influence teaching sick children.

Please download the full Call for papers at: <http://www.hospitalteachers.eu/winfos/news/news.php>.

European Teachers can check out the Comenius In-Service Training funding opportunities at <http://www.hopeinholland.eu/>

Committee Members: don't forget our special days: Monday 8th and Tuesday 9th October 2012



Hospital Organization of Pedagogues in Europe

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