

HOPE Newsletter

March 2023 Editor - Marit Helmholt

EDITORIAL



Dear friends of HOPE

In about two months the HOPE Congress will begin in Italy. We will be guests in Milan where we will be thinking together about 'shaping the Future with Education'. We will share a lot of information with each other -76 presentations have been approved.

I am looking forward to meeting up and learning from each other. And hopefully we will also have time to get to know the city of Milan a little better.

This HOPE newsletter is a precongress edition and will also cover the upcoming HOPE congress. If you are unable to join us for the congress I am sure you will be kept informed by your colleagues and you can also take a look at the website: www.hope22.eu

I wish you lots of patience, strength and above all, joy, in our beautiful work.

Marit Helmholt Editor

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2/ Letter from the President

Let's meet in Milan

Dear members of HOPE, friends and colleagues, it is with great pleasure that I invite you to the 12th HOPE Congress which will take place in Milan (Italy) from May 9 to 12, 2023.

The theme of this HOPE Congress is 'Shaping the future with education: Cultures, Relationships, Competencies'. The Roman philosopher Cicero taught us 'What greater or better gift can we offer the republic than to teach and instruct our youth'. This wisdom is still timeless...



The future remains a challenge, but Albert Einstein put this into perspective by saying 'I never think about the future, it comes soon enough'.

'Unique forms of continuity in space' (1913), by the Italian artist Umberto Boccioni (from the art movement Futurism)

The wonderful HOPE Congress in Poznan (Poland) in 2018 was the last HOPE Congress where we could meet in person. Only six weeks before the start of the HOPE Congress in Tallinn (Estonia) in 2020, all of Europe went into lockdown due to Covid and the HOPE Congress was unfortunately cancelled. After that, the Italian team prepared the HOPE Congress 2022 in Milan. Even then, Covid was still too present for the HOPE Congress to take place. Thank goodness we can meet again in person in Milan in May 2023.

The HOPE Congress in Milan will provide an opportunity for presentations of best practices in hospital education. For Italy it is an inspiring challenge to be the host. The Italian colleagues work as hard as they can to make a big success of this HOPE Congress. Come and share your experiences and interests. Let's create synergies for our efforts to support the right to hospital education and promote improvements in our field of work. Take the chance to network both professionally and socially and enjoy the special atmosphere of a European gathering with colleagues from all over Europe (and the rest of the world!) facing similar difficulties, joys and challenges in their daily work. We look forward to welcoming you all in Milan.

Jan Haverkate, President of HOPE Congress website: <u>www.hope22.eu</u> Vilnius J.Lauzikas Consulting Teaching Center is a hospital school operating in 6 different hospitals at a local and National level.

All teachers of Vilnius J.Laužikas consulting-teaching Center work with students with special needs as well as different somatic and mental illnesses. Teachers pay great attention to finding and developing new teaching methods in order to increase students' learning motivation. Educators realise their mission which is the importance to help a child suffering from different illnesses or having congenital disabilities. One of the non-traditional teaching and learning methods used at the centre is project-based activities. In order to avoid social isolation, students during their stay in the hospital are encouraged to participate in different type of projects at both local and international level (which are supported by the European Union).

Teachers cooperate with medical team closely to discuss activities that have positive influence on students' emotional health, which as a result, has a significant impact on their recovery.

Students who are admitted to the hospital suffer from different mental health problems causing anxiety, fatigue, sadness. The reasons of children's worries are various, including health of loved ones, school performance, uncertainty of the future. In such circumstances, children experience a wide variety of feelings.

The child's anxiety level also depends on the amount of anxiety in the environment.

For the emotional experiences of children and adolescents, it is extremely important to find a safe space for a conversation about their feelings. It is necessary to talk to them as well as for a child to be heard and understood.

One of the simple and yet difficult tasks is purely to get child interested, to be able to find the "key" to him. "We work as a team in the department and the contribution of educators is extremely important in strengthening the child's emotional state. During the treatment process, I noticed how culture and art can help build a dialogue and talk to the child even about the most difficult topics" says Jolanta Trinkūnienė, child and adolescent psychiatrist, the head doctor of child and adolescent crisis intervention department.

One, either it's a child or adolescent, needs a dedicated time and space in order to reflect on emotional experiences - an activity at school encouraging children to relax and reflect on themselves creates that safe environment. You can see the different side of the child

under such circumstances - as an example, there might be instances where the child is not willing to talk at the doctor's office, however they open up once focusing on art etc.

During all these projects a lot of informal education activities were developed. Number of local projects relate to national, European and worldwide events –Independence day, day of constitution, the most beautiful butterfly in the world, Tolerance Day, Climate Week, A dog is a family friend, sports and leisure partner, European language day, European day activities EU projects <u>www.lauzikocentras.lt</u>. Such kind of activities help all students to feel responsible not locally but globally as well. Feeling responsible, not only for themselves, but also for the surrounding environment and the planet, helps children, especially teenagers, to become more self-confident.



The most beautiful butterfly in the world

Participation in project activities help students to feel more integrated into society, social life and develop correction to their peers in different countries. Informal education and project activities help students to avoid gaps in their studies and achieve great results. Initiating and implementing projects helped to develop many international and local seminars for hospitals, sanatoriums and rehabilitation centres for teachers who work with patients with special needs, suffering from chronic and temporarily illnesses.



Workshop "Autumn in Vilnius"

The centre has now joined the new EU Erasmus + project "Protection of animal welfare in school education". The project plan focuses on participation in animal protection and welfare activities, investment in mental healing through zootherapy. Skills and qualifications in animal protection and welfare will be prioritized through best practice exchange and knowledge building. The coordinating institution is WYZSZA SZKOLA BIZNESU I NAUK O ZDROWIU from Lodz, Poland, project partners are from Greece, Spain, North Macedonia schools and Non-Governmental Organisations (NGO's).

Organisations will form a stronger European arts/ culture and media community cooperating across the continent for the benefits of disadvantaged people. Engagement of staff/organisations in debate and cooperation in project activity, skills exchange participation and the analysis of dissemination of project findings will be one of the key objectives for the project

School teachers cooperate with hospital school teachers from over all Europe searching for innovative ways to improve both formal and non-formal educational with students staying at hospital.

Mrs. Irma Vitukynaite is a hospital teacher in Estonia Email address: <u>centrasirma@gmail.com</u>

4/ Two selected abstracts from Continuity in Education

Book Review: My Bodyguard Brain – How Your Brain Uses Pain to Protect You

Author: Huub Vossen (The Netherlands)

Abstract

Review of a practical resource providing children with ongoing pain (and their parents) information of the neurobiology of pain. The book 'My Bodyguard Brain – How your brain uses pain to protect you' explains why we feel pain. The brain makes pain when it notices any sort of danger. Pain is associated with acute injury but it can also be evoked by social interaction and unpleasant emotion that children don't know how to deal with. The text and drawings explain in a child-friendly way how your 'Bodyguard' brain wants to look after you, and how it sometimes gets a bit 'too good' at that job. It is a book I would recommend for teachers and clinicians dealing with children experiencing chronic pain. Ongoing pain in children is a huge problem in society. Paediatric pain should matter to everyone. It affects approximately one quarter to one third of all children and adolescents. Children with chronic pain have often cut back all their normal activities like school, sports, social life and sleep. Almost 60% of these children become adults experiencing pain and 50% of the children with pain has a parent suffering from chronic pain. Understanding what you feel will turn the oversensitive alarm down and is the first step to improve the lives of children and adolescents with pain.

Keywords: worry associated with pain; chronic stress; post-traumatic stress; child disability; epigenetic mechanisms; cognitive behavioural therapy; pain management; pain education; educator resource; paediatric medical conditions; paediatric pain chronic; pain episodic; pain school issues; central sensitisation adolescence; pain nociceptive; plasticity education; fear of pain; anxiety depression.

Year: 2021, Volume: 2 Issue: , Page/Article: 73–75 DOI: 10.5334/cie.31

"My Life in the Hospital": Narratives of Children With a Medical Condition

Authors: Michele Capurso (Italy), Federico Bianchi di Castelbianco (Italy), Magda Di Renzo (Italy)

Abstract

Pediatric hospitalization is a common experience that may increase children's sense of isolation and impinge on their social-emotional wellbeing. Educators and medical practitioners could minimize these negative effects of hospitalization if they were able to listen to the voices of the children and, therefore, better meet their needs. This qualitative study provides an overview of how children with a medical condition actively construct and organize their thoughts and feelings about illness, life in hospital, and relationships. We extrapolated from a collection of children's narratives from a previous more comprehensive study (consisting of 379 narratives from children in 29 public hospitals across Italy, age range 3–14 years). Narratives grouped under the headings "Me and my illness" or "Me and the others" were selected and analyzed using interpretative phenomenological analysis (IPA) to identify the richness and complexity of children's experience. Results showed that children's description of their illness was affected both by cognitive and social factors. For children, the concept of feeling ill or well is not linked only to the fact that they are in hospital for a medical condition; rather, it is influenced by their ability to form relationships with others, play, be active, and feel alive within the hospital environment. Listening to narratives can deepen our understanding of children's illness-related experiences and how they make sense of their situation. A set of practice implications are presented to help health professionals and educators to improve their listening capabilities and better prevent adverse pediatric hospitalization outcomes.

Keywords: Children' narrative, hospital, play, relationships, interpretative phenomenological analysis

Year: 2021, Volume: 2 Issue: 1 Page/Article: 4–25. DOI: 10.5334/cie.12

Interested? Check out more: <u>https://continuityineducation.org/articles/</u>

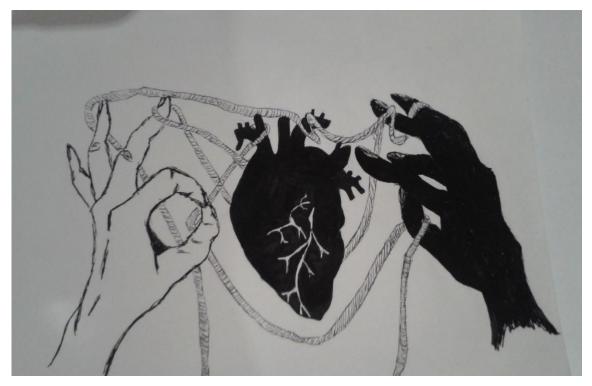
Remember that the Academic Journal Continuity in Education is sponsored by the major hospital teachers' associations worldwide and all the journal articles are completely free.

Michele Capurso (Chief editor of the Academic Journal "Continuity in Education") Email address: <u>ciejournal@unipg.it</u> 7

5/ Art by students with medical and/or mental health needs



Wiktoria 11 (Poland)



Julia 18 (Poland)

6/ Workshop Basic Bookbinding (to do even in bed)

In this workshop "Basic Bookbinding" at the HOPE congress in Milan you will learn how to make books with children from six years old up to eighty years old. The books are made of old juice packs and some blank sheets of paper.

RAGS make paper, PAPER makes money, MONEY makes banks, BANKS make loans, LOANS make beggars, BEGGARS make RAGS.

RAGS make paper, PAPER makes money, MONEY makes banks, BANKS make loans, LOANS make beggars, BEGGARS make RAGS.

The books are made of old juice packs and some blank sheets of paper. This book has two secret storage compartments and the closure of the juice pack is used as the closure for the book. You don't need special tools to make these books. In fact you only need a few simple tools like a pair of scissors, a needle, a nail, a ruler, a pencil and four clothespins (probably available in every household). The participants of this workshop do not need to bring any tools or materials for this workshop. Just your bare hands are sufficient.

The books look like this.





A good book is the best of friends, especially a nice book made by your own hands.

The student with medical or mental health needs can even make such books in bed. It takes about 30 minutes to make such a book. The real material costs for such a book are no more than € 0,10 for each book. At the HOPE congress in Milan in May 2023 you can make such a book for free.

This workshop offers many ideas how to use the handmade books for students with medical or mental health needs. In the room of the workshop you will find an exhibition of 30 different books, all made of old juice packs with the same techniques for bookbinding, which I will teach you in the workshop. Please, do try this at home!

All this looks very well on paper, but in practice it is even better. Book your bookbinder in time. Look at the website of the HOPE Congress in Milan to register for this workshop.

Jan Haverkate, hospital teacher in the Netherlands and bookbinder Email address: <u>jan.haverkate@ijsselgroep.nl</u>

7/ Education Never Stops!

The concept of the Hospital School has now become a reality and the P.A.V.E.L Association continues a project that responds exactly to the concerns of teachers and parents regarding the teaching of students with special needs. Association P.A.V.E.L. is permanently involved in supporting the education and schooling of student patients from the clinics in the Fundeni area of Bucharest.

On December 5, 2022, the 6th edition of the Science and Arts Olympiad was organized for students from grades V-XII. We gave the chance also to the primary school pupils, organizing the "Little Scholars" competition for younger students. The subjects were interactive and interdisciplinary, and the full engagement and participation of children and adolescents was possible in a hybrid format, either with their physical presence in the hospital rooms, or in an online environment for those at home, during the therapeutic rest. The turnout was impressive. So were the emotions, especially of the parents. On December 6, by St Nicolas day, the P.A.V.E.L. Association awarded the winners by holding an artistic event and offering special prizes consisting of books and special supplies for school. We thank DELL Romania for financing this project that allowed the organization of complementary education for children and young people in hospital. We thank Herlitz Romania for providing the special supplies for the prizes and we thank the students from Dimitrie Cantemir University, guided by Prof. Univ. Valentin Popescu, for their contribution to this event.

I must also especially thank a person who serves education every day, Magda Jianu, a university professor and volunteer in the hospital, a person who has been acting with the desire for education among children and parents in hospitals since 2015.

Association P.A.V.E.L. was concerned and willing to meet the educational and social needs of children and young people with oncological diagnoses and treated in the clinics of oncology and haematology in Bucharest. I thank the president of the association, Olga Cridland, a career teacher and the main supporter of this project, I thank Beti and Gabriel, fellow teachers who are present in hospitals for carrying out the education act, and I thank the volunteers and specialist colleagues who are always with us!

Let's meet again with good health, courage and hope at the Science and Arts Olympiad for students in Hospital School - patients in 2023!

Mihai Benchea, Project Manager and Hospital Teacher in Romania HOPE Committee member

Email address: mihai.benchea@asociatiapavel.ro

8/ Fotinica Gliga – In memoriam



With great regret we inform that Fotinica Gliga, our dear colleague from Hospital school in Romania, she has lost for life on the first day of 2023.Fotinica was A TEACHER constantly took action for children with special educational needs. She has been member of core group which proposed the changes and adapted methods for those children from hospitals. Since 2010 as volunteer, Fotinica has been involved in field of education and pedagogic activities for in children hospitals from Bucharest. She participated at the

founding of the association of teachers and educators working with children/teenagers in hospitals. In the same time, she has been member of organizing committee for the HOPE congress in Bucharest (the ninth edition – November 2014). She was a teacher and a promotor for the right of education for all children in special medication situation. She was a brave volunteer and specialist of Association P.A.V.E.L., she was a dedicated hospital teacher and she was the first president of hospitals teachers network in Romania - APES.

Fotinica was one of the pillars of strength the hospital school in Romania. Whether she was very demanding, rationale and objective, finally she was friendly and warm with pupils and parents in hospitals or in online. For sure, Fotinica was the right person in the right place, at the right time. Hospital school concept is associated for many times with her name, she was one of the founders and member of organizing, staffing, projecting and volunteering for education for all.





Fotinica was special person, with a wise voice and a pure hearth, ready to listen you and help persons in need.

Fotinica, we will never forget you and we will remember always your patience, perseverance and dedication to the education of everyone, especially those who face unwanted medical problems.

I would like to end with the

verses written in these days by Nicuşor Gliga, Fotinica's husband:

Darkness? Not. The light is always with me People ask me, shyly At the night I don'have nightmares I get special light Through two beloved lighthouses

Olga Cridland, Mihai Benchea and all colleagues from Association P.A.V.E.L. – Hospital School Program



9/ This one student - Lifeline

Mother asks if I have time to talk to him. He's worried.

Logical, is my first thought. Just turned 12 and then being told that you have a tumor in your brain stem, which there is no cure for. Way too big things to worry about. Confronting your own mortality at such a young age is simply not appropriate... period!

In the car I wonder what he wants to discuss with



me. He doesn't tell his parents much, he lets medical tests and results come over him. And then quickly return to the order of the day: going to school and playing football. Although he notices that everything is becoming more and more difficult for him. Cycling to school no longer works well, the uneven grass makes him trip too often during football and a school day is so full of stimuli that he first has to sleep on the couch for half an hour at home in the afternoon.

I see him for the third time this month. And every time I am startled by the speed with which his body is failing him. Step by step, cancer takes away pieces of his carefree life. The nasty side effects of the dexamethasone add to that. He gains weight by the day, making it even more difficult for him to control his body. And his cheerful, mischievous appearance changes into a flat, expressionless mimicry. But I now know that this is only the outside. Inside he is still that lively boy, full of dreams about the future.

I try to mask my shock and greet him warmly. Together with his mother we look for a quiet place in the school and when I ask what he wants to discuss with me, the word is out. The Final Dutch School Test is coming. He says that he would like to participate, but is so afraid... afraid that he will not be able to pass the Final Dutch School Test, that he will completely screw up and then not get the highest school advice he hopes for.

I always have to let it sink in for a while what lies behind such concern. For me, the Final Dutch School Test is a monstrosity, a measurement that does not do justice to the development of children and a poor predictor of the developments of children. In my head the first reaction to his question is: who cares about that Final Dutch School Test, it is completely unimportant now. But it's not about me. For him, the Final Dutch School Trest is a moment to show what he has to offer and an admission ticket to the school he wants to go to. And in doing so, he confirms to me what I have already learned from others: that the development of children and young people does not stop at a limited life expectancy. Development continues, until the last day! And that requires us as adults to join in. The future is only gone when life stops. Not a moment before that.

And now he asks for help, to clear the way for further development. And I feel a huge urge to do something for him.

Making the Final Dutch School Test turns out to be easy to adapt: he can make the test in smaller pieces and choose the moments that he wants to work on it. And the teacher reassures him: he will always receive the highest school recommendation, regardless of the result. So, two hurdles taken.



Now the biggest yet: ensuring that the intended secondary school is prepared to hire.

His parents want... can't take that step now. I understand that very well. They live by the day and with their enormous fear that he will not be there at all when the next school year starts. But he needs certainty about his future, fully aware that he may not make it.

Children who know they will die early live on two trails: the trail of hopes, dreams and plans for the future and the trail of brutal reality. They need both to continue living. And so we agree that I will contact the new school and ask them to accept him, despite his poor prognosis. It requires a lot of tact and attention, but it works. What makes him very happy, winning the Euro Jackpot Lottery is nothing compared with that.

In the weeks that follow, his energy decreases noticeably and he becomes more and more a prisoner in his own body. The loss of his speech hurts him the most. He can only show his frustration at this with silent tears on his immobile, flat face.

But he still goes to school, every day, sometimes for a few hours, sometimes just half an hour. But he wants and he will. And so his parents bring him with love and the class welcomes him with open arms, every day. He enjoys all those moments, which always make him realize that he is more than his illness, and which do not leave him helpless to wait for the inevitable end.

In the week before the final school musical he dies, peacefully at home. He was still at school the day before. He would have loved to say goodbye to his class and his school together, but just before the finish line his illness caught up with him.

Looking back, I feel how his connection to school was like a lifeline to him. That line not only kept him going during his illness, but was so much more. He felt part of a group (a classmate and not just a patient), a boy with qualities and grew from everything he could still do, until the last day. And no bucket list can beat that.

Mrs. Tanja van Roosmalen is a mourning and loss therapist, remedial educationalist in the Netherlands.

Email address:tanjavanroosmalen@lefverliesbegeleiding.nlWebsite:https://www.lefverliesbegeleiding.nl/

10/ HOPE around the world

Pieter Ceizer was born in Amsterdam in 1982. As a child, he could regularly be found on the Museumplein where he saw alternative art (skateboard halfpipe, graffiti, etc.) come and go. He wanted that too. In 2019 he designed this sparkling image of HOPE. It is the shape of a hand, a signature of the artist at that time. The image of HOPE should provide a counterbalance to the gloomy times during the corona pandemic. The artist himself said that this work was inspired by Robert Indiana (appearance) and Andy Warhol (flowers, cheerfulness and energy).



HOPE sculpture at the Museumplein in Amsterdam (the Netherlands)

11/ Shaping the future with Education: Cultures, Relationships, Competencies

The organisation of the 12th HOPE Congress in Milan, from 8 to 12 May 2023 is progressing well. We have more than 70 confirmed presentations from 22 different counties, ranging from the Americas to New Zealand and Australia. The congress website provides a live registration map (see Figure 1), and the registration counter shows that the astonishing number of 230 participants has been exceeded, probably making this the biggest Hospital Teachers congress ever.

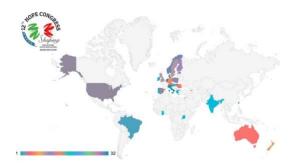


Figure 1 Live registration map from the congress website as of March 15: www.hope22.eu/congress/registration/statistics

The HOPE board has visited the conference venue and met the organisers in February, at the Palazzo delle Stelline, conveniently located in the centre of Milan, close to the train and the metro station. The conference centre has 20 meeting rooms and meeting rooms of various sizes and capacities.



Figure 2, View of the Stelline Conference Centre

Many other accommodations are also available in the area and within the reach of the underground train and are listed at <u>www.hope22.eu/congress/hotel-information</u>.

We have prepared a rich social and cultural programme for those who plan to stay a few more days, before or after the congress. You can view the full programme and make your reservation here: www.hope22.eu/congress/programme/cultural

Finally, the full congress programme is now complete and you can register for the congress sessions and other activities here: <u>www.hope22.eu/congress/registration/sessions</u>

The organising committee started working two years ago and is now ready to welcome you to Milan. Please complete your registration, your hotel and travel reservation, and choose your programme sessions by April 15.

Michele Capurso, member of the organising team of the HOPE congress in Milan.Email address:michele@capurso.net

12/ Proxy Voting Form

HOPE General Assembly, Milan in May 2023 PROXY VOTING FORM

I,	(FULL NAME IN CAPITAL LETTERS)
from	(COUNTRY)

being a member of HOPE, hereby appoint

(NAME OF PERSON YOU WISH TO GIVE YOUR RIGHT TO VOTE TO, FULL NAME IN CAPITAL LETTERS AND COUNTRY)

or if the above person is unavailable, I appoint as my second choice

(SECOND CHOICE SHOULD FIRST NAMED PERSON BE UNABLE TO VOTE, FULL NAME IN CAPITAL LETTERS AND COUNTRY)

as my proxy to vote in my name and on my behalf at the General Assembly of HOPE, to be held in Milan, on Friday, 12th of May 2023 at 9.00 - 11.30 pm. and at any adjournment thereof.

(SIGNATURE)

_	//	
	(DATE)	

This document can be downloaded on the website: www.hospitalteachers.eu

If you are unable to attend the General Assembly, please forward the completed form to a member of HOPE who will attend the General Assembly.

13/ Ukraine - I feel sorry / I feel hope



Γ



I feel sorry	I have hope
for the people who see their homes go up in smoke	for the people who see their homes go up in smoke
who flee from the bombs that come down	that the bombs soon stop, they can go home
around their heads and touch all that is dear to them	and rebuild all that is dear to them.
I feel sorry	I have hope
for those who are homeless and do not know where to	for those who are homeless and receive help
get help from the raging planes that	from the least expected places and find peace
plant nightmares in their minds never to go away	so that the nightmares quickly fade into a distant dream
1 feed commu	
I feel sorry	I have hope
for the Russians waiting at home watching their country sow	for the Russians watching at home how their country
death and destruction amongst people they know as	shuts down this pointless war,
friends and family	see their friends and family being spared
where many want to get up but don't dare or disappear	and they too may discover the power of free speech
I feel sorry	
for the soldiers who have to fight against	I have hope
	1

neighbors they do not know and do not wish any harm	for the soldiers who no longer want to fight against
but have to for else their own life is worth nothing	neighbors they know and never will hurt them
anymore	so they too can live on without fear
I feel sorry	
for the leaders of our world who must decide how to	Do I have hope
respond to this I don't know what the right word is to describe	for the leaders of our world to quickly decide,
what is happening now to our 'civilization' but what they have to solve	respond adequately to this wrongful act of appropriation
	and prove that our "civilization" is entitled to that name
l feel sorry	
for the man responsible for what is happening now who condones	Do I have hope
without visible emotions or scruples, well substantiates with an endless list	for the man who does not consider himself responsible for what is happening and with
of non-arguments why he is destroying the lives of so many	emotions can put an end to the senseless violence, the painful
	bloodshed and the destruction of so much innocence
I feel sorry	
for us	
	I have hope
	for us

This double poem has been written and submitted by the Belgian poet Luc Vos: "I wrote this poem when I was tossed back and forth between incomprehension and disbelief. I hope that my words can help to bring comfort somewhere."

Luc Vos, poet

Email address: <u>luc@lucvos.be</u>



14/ Word of thanks

You are most welcome to share your experiences of hospital schools.

Your ideas may become an inspiration for our colleagues working within the hospital schools in other countries. So, please, feel free to send in articles for the September Newsletter.

I would like to express my gratitude to Jan Haverkate for constant help and Martin Dixon for the technical support and for the native language corrections.

Marit Helmholt

Email address: <u>newsletter@hospitalteachers.eu</u>

