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## LETTER FROM THE CHIEF EXECUTIVE

Dear Friends,

This past year has seen a surge in interest in palliative care for children, with initial training courses and new programmes in a number of countries in different regions of the world. This is both exciting and challenging – exciting as it means more children will have access to palliative care; and challenging as we try to link programmes for mentorship and support, and meet the increasing requests for education or support for attendance at conferences and workshops. The ICPCN e-Learning courses have shown to be useful for many professionals and the new translations into Spanish, Russian and Serbian, with more modules and language translations to come, will make the courses even more accessible. We are in the process of setting up a Virtual Learning Environment for e-learning courses on pain management and palliative care, in collaboration with the Global Access to Pain Relief Initiative (GAPRI) and the African Palliative Care Association (APCA), and discussing more ways to develop this important movement in palliative care through partnerships and collaboration.

The ICPCN is steadily building up a register of palliative care practitioners willing and able to assist with training in different countries, and to mentor developing programmes. The world of palliative care for children contains amazingly generous practitioners, who enjoy sharing their expertise and knowledge.

We are also delighted to be working with UNICEF on research that we believe will provide a better indication of the number of children who would benefit from palliative care. Dr Kathy Foley, opening the 1st European Paediatric Palliative

Care conference in Rome, stated that she believed that we should be able to reach these children, as the number will not be unattainable. The ICPCN supports this belief and we further believe that as we work together and go forward strategically, it can be done.

An aspect that is often neglected is bereavement support, and the recent tragic shooting in Connecticut in the US, of young school children and their teachers, has highlighted the importance of strong bereavement programmes within children's palliative care, that can be a compassionate resource at times such as these. Our response can be read on our ehospice page.

This is the last quarterly newsletter, since the ICPCN now has an edition of ehospice at [www.ehospice.com](http://www.ehospice.com) with up-to-date news on palliative care for children and extra information on the ICPCN website. We will also continue to keep you updated through bulletins. I would like to thank Sue Boucher for the wonderfully professional and informative newsletters and for her excellent editing of the international children's edition of ehospice.

As we go forward into a new year, may we all work together to make this world a better place for children and families facing life-threatening conditions.

Be blessed at Christmas and always,

*Joan*



## GOODBYE AND THANK YOU TO THE 'DIANA FUND'

*Diana*

Princess of Wales Memorial Fund  
**THE WORK CONTINUES**

The ICPCN would like to express its deepest gratitude to **The Diana Princess of Wales Memorial Fund** for

all the support that it has shown us since our inception in 2005. It has been a great honour to work with the wonderful people from this fund who have always provided

wise counsel along with their much needed financial support in vital areas of our work.

We were deeply honoured to be a recipient of a legacy grant, made by the fund to 44 long term partners "whose work is continuing to improve the lives of disadvantaged people in the UK and around the world."

Joan Marston, ICPCN Chief Executive attended the closing function held at Kensington Palace on Thursday 29 November.

## INTERNATIONAL EVENTS CALENDAR: JANUARY - APRIL 2013

More information and contact details for all these conferences, courses and events can be found on our website. Go to [www.icpcn.org.uk](http://www.icpcn.org.uk)

## January

10	Making every moment matter in the classroom	Oxfordshire, UK	<a href="http://www.sobell-house.org.uk">www.sobell-house.org.uk</a>
10 - 11	Chronic Pain Management 2013	London, UK	<a href="http://www.mahealthcareevents.co.uk/pain2013">www.mahealthcareevents.co.uk/pain2013</a>
15	Child Protection and Safeguarding - Legal Masterclass	London, UK	<a href="http://www.healthcareconferencesuk.co.uk/child_protection">www.healthcareconferencesuk.co.uk/child_protection</a>
29	The Neonatal Experience - Loss and Grief without Bereavement	Newcastle upon Tyne, UK	<a href="http://www.childbereavementuk.org">www.childbereavementuk.org</a>

## February

6	The Neonatal Experience - Loss and Grief without Bereavement	London, UK	<a href="http://www.childbereavementuk.org">www.childbereavementuk.org</a>
25	3rd Annual Conference National Development and Neonatal Palliative and End of Life Care	Buckinghamshire, UK	<a href="http://www.childbereavementuk.org">www.childbereavementuk.org</a>

## March

21	Making every moment matter in the classroom: Using creative methods	Oxfordshire, UK	<a href="http://www.sobell-house.org.uk">www.sobell-house.org.uk</a>
10	American Academy of Pain Medicine: 29th Annual meeting	Fort Lauderdale, USA	<a href="http://www.painmed.org">www.painmed.org</a>

## April

16	Supporting Parents through Pregnancy, Loss and the Death of a baby	Manchester, UK	<a href="http://www.childbereavement.org">www.childbereavement.org</a>
24	2013 Annual Hospice Palliative Care Ontario Conference	Ontario, Canada	<a href="http://www.hppo.ca/conference">www.hppo.ca/conference</a>
29	The Neonatal Experience - Loss and Grief without Bereavement	Buckinghamshire, UK	<a href="http://www.childbereavement.org">www.childbereavement.org</a>

This is the *last* ICPCN quarterly e-Newsletter. So much is happening in the world of children's palliative care we need to find better ways to bring our members the news as it happens or soon afterwards. You can stay up to date on what is happening by...

## SIGNING UP FOR REGULAR EHOSPICE ALERTS ...



# ehospice



Successfully launched in October, ehospice is a free website and app that brings you real time international news and intelligence on hospice, palliative and end of life care – delivered by regional and national hospice and palliative care organisations worldwide. The International Children's Page is updated weekly.

At the mere touch of a button,

you will find the latest news, commentary and analysis from across the world, bringing together the expertise and experience of the global hospice and palliative care community.

Subscribers are able to select which alerts they wish to receive and from which categories. These alerts can also be cancelled by a very simple process on the site.

As this is the last of the quarterly ICPCN newsletters, we would like to encourage our members to keep up to date through the ehospice site or via the app. The International Children's page of this site is edited by ICPCN.

To sign up for regular email alerts and updates go to:  
<http://www.ehospice.com/internationalchildrens/registration.aspx>

## ... AND JOINING OUR FACEBOOK PAGE



Our ICPCN Facebook page is slowly growing in popularity and we would like to encourage all our members with a facebook account to 'Like' our page in order to spread

the word and the work of the ICPCN even further afield.

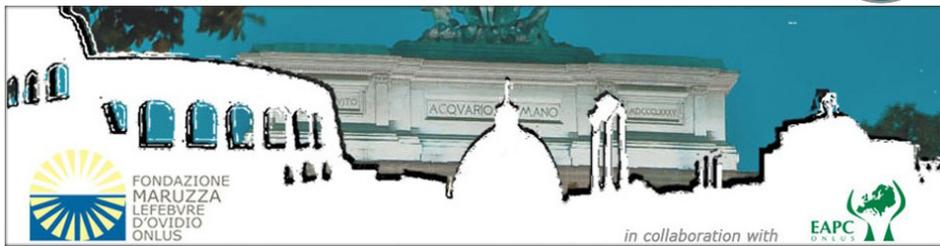
Social Media has become a quick and easy way to spread information and will be another way in which important news and updates are brought to your attention.

Go to:  
<http://www.facebook.com/ICPCN?ref=hl>



# REPORT ON THE 1st EUROPEAN CONGRESS ON PAEDIATRIC PALLIATIVE CARE IN ROME

## 1st EUROPEAN CONGRESS ON PAEDIATRIC PALLIATIVE CARE



*The congress brought people together from around the world. From l to r: Dr Sue Fowler-Kerry (Canada) Dr Anna Garchakova (Belarus), Dr Stefan Friedrichsdorf (USA), Busi Nkosi (South Africa), Dr Delia Birtar and Marinela Murg (Romania)*



*Barbara Gelb, Chief Executive of Together for Short Lives and ICPCN Co-Chair presented on developments in the UK*

On the last day delegates were given a chance to hear of new strategies for the treatment of pain from Dr Stefan Friedrichsdorf and about 'Sleep disturbance and daytime agitation in severe neurological conditions' from Dr Boris Zernikow. Dr Joanne Wolfe ended the early morning session with an interesting presentation on 'End-of-life management.'

The session before lunch focused on rare diseases and also looked at the neonatal screening of newborns for a number of rare diseases. The afternoon saw an inspiring session, chaired by Lizzie Chambers from Together for Short Lives where Ulrika Kreichbergs spoke on communication, Danai Papadatou from Greece reminded delegates of the importance of self care and care for the team and Myra Bluebond-Langner, the True Colours Trust Chair in Palliative Care for Children and Young People appealed to delegates to consider a more multi-dimensional and ethnological approach to research in the field. Conference organisers have indicated that the presentations from the conference will be available for download in due course.

The conference was closed at 17:45 by Sylvia Lefebvre D'Ovidio, President of the Fondazione Maruzza Lefebvre D'Ovidio Onlus (The Maruzza Foundation) who acknowledged all those who played a role in the great success of the very first European Paediatric Palliative Care Congress. She stated that the 2nd European Paediatric Palliative Care Congress would be held in 2014, and a venue found that could easily hold the large number of delegates that there is no doubt would wish to attend.

The 1st European Paediatric Palliative Care Congress held in Rome from 28 - 30 November 2012 was attended by over 300 delegates. This was more than double the number originally expected and stretched the unusual and very beautiful venue, the Acquario Romano, to its full capacity. By early November the organisers had to regretfully close registration as the venue could not comfortably hold any further delegates.

Presentations were heard from practitioners from all over Europe to delegates from as far abroad as Uruguay, South Africa and

Australia. After the inspirational opening ceremony on Wednesday evening, the congress began on Thursday morning with an overview of developments in the field of children's palliative care from around Europe. Paediatric Palliative Care leaders from Italy, France, Germany, Belarus, Russia, Romania, Greece, Switzerland, Spain, Ireland and the United Kingdom, spoke of the various models of children's palliative care provision found in each of these countries, their successes and challenges. The second half of the day was dedicated to the experience of families in paediatric palliative care.

## FUNDERS AND LEADERS IN PPC MEET IN ROME

A historic meeting between funders and potential funders in the field of children's palliative care and leaders in the field from around the world took place at the Una Hotel in Rome on Saturday 1 December 2012.

Organised by the Open Society Foundations (OSF), the International Children's Palliative Care Network

(ICPCN) and the Fondazione Maruzza Lefebvre D'Ovidio Onlus, a meeting was arranged between representatives of funders who have in the past contributed substantially to the development of children's palliative care internationally, along with those who were new to the cause and international leaders in the field of children's palliative care.

A full report on this meeting will be made available on the ICPCN website. Presentations and various handouts from the meeting can be viewed and downloaded from [http://health.accel-it.it/en/seminar/pediatric\\_palliative\\_care\\_funders\\_meeting/](http://health.accel-it.it/en/seminar/pediatric_palliative_care_funders_meeting/)

Read more on the ehospice website.



Photo courtesy of Ja, til lindrende enhet og omsorg for barn

Photo courtesy of Fabio Mazzarella

*Dr Richard Hain with his award, which was presented to him by Sylvia Lefebvre D'Ovidio, President of the Fondazione Maruzza Lefebvre D'Ovidio Onlus and Dr Dott. Gianni Letta*

*Dr Anna Garchakova, Founding Director of the Children's Hospice of Belarus with her award.*

*Dr Franca Benini, was honoured with the 'No pain for children' award for excellence in palliative care from Dr Giampaolo Albertini, President of No Pain for Children*

There were three worthy award winners at the opening ceremony of the 1st European Paediatric Palliative Care Congress on Wednesday 28 November 2012.

The ICPCN congratulates the two deserving winners of this year's prestigious *Vittorio Ventafridda Award*. Both winners are leading lights in children's palliative care and have contributed enormously to the field. Dr Richard Hain, Consultant in Paediatric Palliative Medicine and co-editor of *The Oxford Textbook of Palliative Care for Children*, was honoured for his wide reaching contribution to the field not only in Europe and the UK, but worldwide.

Dr Anna Garchakova founded the very first children's hospice in Minsk, Belarus which was also the first children's hospice in the whole of the former Soviet Union. Under Anna's passionate and competent leadership, this organisation

has introduced a broad range of children's palliative care services including home care, day care, in-patient care and bereavement support to the children of Belarus and their families. The services have also expanded to other cities within the country. Anna was a founding member of the ICPCN Steering Group and is a most worthy recipient of this award.

Another worthy award winner at the opening ceremony of the 1st Paediatric Palliative Care Congress in Rome was Dr Franca Benini, Head of the Paediatric Palliative Care and Pain Service of the Paediatric Department of Padua University (Italy). She is a leading Researcher in Pain Therapy and Palliative Care in Newborn, Children and Adolescents as well as a Senior Lecturer at the Faculty of Paediatrics at Padua University. Dr Benini was honoured with the 'No pain for Children' award for excellence in palliative care.

### The Vittorio Ventafridda Award

Vittorio Ventafridda was the pioneer of palliative care in Europe. A medical professional who led the way based on compassion and respect for the dignity of those who are seriously ill. He built a foundation of knowledge that continues to gain consensus and acknowledgement today. He demonstrated models of scientific excellence, of moral principals and compassion, all essential qualities for those who choose to dedicate their lives to this cause.

Each year this accolade, created in his honour, aims to recognise outstanding initiatives and enterprises that have made a difference to the quality of life of patients and their families.

It aims to celebrate the achievements in all the areas of palliative care in the social and medical contexts; in scientific and humanistic research, in education and voluntary programmes and, above all, in the expression of moral values.

## Please sign the EAPC Prague Charter

Access to palliative care is a legal obligation, as acknowledged by United Nations conventions, and has been advocated as a human right by international associations, based on the right to the highest attainable standard of physical and mental health. In cases where patients face severe

pain, government failure to provide palliative care can also constitute cruel, inhuman or degrading treatment. Palliative care can effectively relieve or even prevent this suffering and can be provided at comparably low cost.

Yet, the governments of many countries

throughout the world have not taken adequate steps to ensure patients with incurable illnesses can realise the right to access palliative care.

To sign this charter, go to: [http://www.avaaz.org/en/petition/The\\_Prague\\_Charter\\_Relieving\\_suffering/?pv=27](http://www.avaaz.org/en/petition/The_Prague_Charter_Relieving_suffering/?pv=27)

Joan Marston describes her recent visit to Indonesia and the growing concern over children with HIV



***Joan Marston, Chief Executive of ICPCN spent a week in Jakarta, Indonesia earlier this month at the invitation of Lynna Chandra, founder of Rachel House, to assist in raising awareness of the need for palliative care for children in this country.***

Indonesia is a country with a population of 242.3 million and Jakarta, capital of Indonesia, is South-East Asia's largest city with a population approaching 12 million. In 2011 as many as 5,555 women and babies were identified to be living with HIV and AIDS in the city. A combination of stigma and lack of knowledge means that at present only 5 to 10 % of people living with HIV are being diagnosed. To encourage people to be tested and treated, the Jakarta Health Authority has launched a free service for all medical care related to HIV and AIDS for residents of Jakarta in community health centres and hospitals.

At present there is only one home care programme providing palliative care for children with cancer and advanced HIV. Rachel House children's hospice has been providing care at home to children nearing the end of life, with both cancer and HIV, for three years.

Five nurses, travelling on extremely busy roads by motorcycle, cover the four regions of Jakarta caring for very sick children and supporting their families, with compassion and expertise.

Joan Marston, chief executive of the ICPCN, was invited to Jakarta by Lynna Chandra, founder of Rachel House, to assist in raising awareness of the need for palliative care for children, and especially for children with HIV. Joan visited two families living in very poor circumstances, each with a very ill little boy suffering from severe malnutrition, opportunistic infections and pain, and observing the emotional pain of the families. "It felt like I had gone back in time to the terrible early days of the HIV epidemic in South Africa," she said afterwards.

Joan spoke at the inaugural meeting of a network of organizations caring for children with HIV, arranged very successfully by Rachel House and reports that presentations on the need for palliative care for children with HIV elicited very positive responses from those attending. Further presentations at the RSUD Tarakan Public Hospital in West Jakarta, the RSPI Suliarti Saroso National Infectious Diseases

Hospital, and the Clinical Research Meeting of the Indonesian Association of Physicians in AIDS Care provided an opportunity to stimulate interest in palliative care for children, as well as in the community care model of Rachel House.

The model of home care developed by Rachel House could become a model for Indonesia where the rising HIV numbers will call for a strengthening of the community response. Dr Edi Tenuteru, a member of the ICPCN and a paediatric oncologist who is a supporter of Rachel House and a strong advocate for palliative care for children in Indonesia, met with Joan and described a successful project he has initiated to train people in his church in palliative care.

## Rachel House

Yayasan Rumah Rachel (Rachel House) is a paediatric hospice providing end-of-life care for children with life-threatening conditions such as cancer and HIV, providing palliative care for children from families who cannot afford medical care.

In 2004, Lynna Chandra, an investment banker who had watched a close friend battle and lose her life to cancer, began a journey to explore the need for a safe haven to provide end-of-life care for children in the poorest parts of Asia. Rachel House commemorates the life of her friend, Rachel Clayton, who showed those around her that no matter how sick you are, life can be lived to the fullest with dignity and joy when surrounded by loving attention and care.

The vision of Rachel House is to never see a child die alone, without love and care and its mission is to provide palliative care for children with life-threatening conditions, allowing them to live with joy and dignity in a non-discriminatory, safe and loving environment.

Learn more at:  
[www.rachel-house.org](http://www.rachel-house.org)



### According to WHO and UNICEF, as many as 3.4 million children worldwide live with HIV / AIDS



For World AIDS Day on 1 December, the ICPCN approached Sister Helen (Topsy) van Zyl from Golden Gateway Hospice in South Africa, a country with more AIDS victims than any other worldwide, to tell us about their role in caring for children who are HIV positive. This is the moving story of a 7 year old living with AIDS and the people at the hospice who care for her. She is referred to as Dineo in this story, although this is not her real name. The pictures show the progress of Dineo from presentation at hospice to the present day.

Golden Gateway Hospice nurse, Helen (Topsy) van Zyl, remembers well her first encounter with 7 year old Dineo. She recalls the day in November 2011 that Dineo's granny brought her to the hospice. "Even at age 6, Dineo was so small, emaciated and weak that her grandmother carried her on her back like a baby. She had been diagnosed as HIV positive the previous month and her grandmother later told me that they had come to accept that it was time for Dineo to 'go to her ancestors'."

At the time of Dineo's initial assessment she was malnourished and anaemic. Van Zyl relates that Dineo's skin was dry, she was suffering from severe thrush, had diarrhoea and vomiting and all her glands were swollen. Her liver was enlarged and tender and she had abdominal distension. She was also coughing and was very sleepy and uncommunicative. She was unable to walk and had reached very few of her normal developmental milestones.

Van Zyl wasted no time in having Dineo admitted to the local hospital, where she was started on ARVs as well as treatment for all her other symptoms. They were thankful to hear that she did not have TB, an often deadly co-infection of HIV. A week later, she was discharged from the hospital and went back to her home - a shack that she shares with her grandparents and 10 other family members. Both Dineo's parents are deceased and only three people living in this informal home bring in any income.

"This is not an unusual situation for many of our patients," says van Zyl. "Hospice nurses and home based carers are often confronted with such extreme poverty. We do what we can to alleviate not only the physical suffering of our patient and their families, but also give social, emotional and spiritual support."

For Dineo, this support from Sister Topsy van Zyl and the staff at Golden Gateway Hospice has been her lifeline. She is visited weekly by a carer who monitors her health and makes sure that she is taking her medication. If there is a problem the carer reports this immediately to the nursing sister who will go and see Dineo and refer her to a doctor or to the hospital if necessary. Ongoing conversations assist her carers to provide the appropriate care for a HIV positive child. The nursing sister sees Dineo monthly to weigh her and to answer any questions that she or her carers may have. The family is also supplied with nutritional supplements when these are available at the Hospice. "When Dineo was very sick she had no appetite so we gave her nutritional sips which she could drink once a day," says van Zyl.

#### 'She is my miracle girl'

In addition, the hospice Social Worker has done a full psychosocial assessment on Dineo and her family. Counselling was provided to the family and she continues to receive emotional support through her attendance at a support group. A referral was made to a networking partner who assisted the family to obtain a grant for Dineo. At present the Social Worker is working with the hospice's proposal writer to obtain funding to enable the family to purchase a school uniform for Dineo and for the other children in the home.

"Now she is my little miracle girl," says van Zyl proudly "and she is starting school next year."

There is no doubt that when Dineo's first school day arrives, Sister Topsy van Zyl and the staff of Golden Gateway Hospice, will be there, cheering her on.

### HIV/AIDS Statistics

The latest figures from the World Health Organization (WHO) and UNICEF estimate that 3.4 million children worldwide were living with HIV at the end of 2011, 91% of them in sub-Saharan Africa. The United Nations estimates that around 370000 children below the age of 15 years are infected every year with the virus. Most of these children acquire HIV from their HIV-infected mothers during pregnancy, birth or breastfeeding. Although mother to child transmission can be significantly reduced, such interventions are not yet widely accessible in countries with limited resources.

Children on ART still often have to deal with pain and other symptoms. They also often fall victim to opportunistic infections. Added to this burden, children with HIV often develop slowly and need interventions that address developmental delays, both cognitive and physical. And children who have lost one or both parents to AIDS are also in need of considerable psychological, emotional and social support, which palliative care provides.

The ICPCN sees palliative care for children as a human right and calls on all governments to provide children's palliative care. For effective palliative care provision the following is needed:

- ▶ training in children's palliative care for all health and allied professionals
- ▶ relevant policies
- ▶ systems to provide care at primary, secondary and tertiary levels
- ▶ equitable access to pain-relieving and other palliative medicines, including opioids
- ▶ adequate funding

## Next round in ICPCN Delphi Study on research needs in PPC

ICPCN is in the process of undertaking a Delphi study on priorities for global research into children's palliative care. Members have previously been invited to take part in the study.

The Scientific Committee of the ICPCN would like to thank everyone who took part in the first round of the Delphi study and invite all ICPCN members to take part in the next round of the Delphi process.

The main purpose of the study is to identify the global priorities for research in children's palliative care that can inform the development of a research agenda for the ICPCN and its partners. The resulting research priorities will

be used for the following purposes:

- ▶ Serve as a guide to inform the development of an international research agenda for the ICPCN
- ▶ Inform the development of collaborative research studies on children's palliative care
- ▶ Provide the evidence base to justify proposed research
- ▶ Influence funders to provide funding for international children's palliative care research

The key for this to happen is to prioritise areas for research into children's palliative care that will benefit from international collaboration and have the most impact on the quality of care for children and their families. The

identification of such priorities will likely push the research agenda worldwide and beyond the remit of the ICPCN. It is hoped that these priorities will serve as a baseline which international health care providers may build upon to develop research in the field of children's palliative care.

The questionnaire is being administered online and can be accessed at: <https://www.surveymonkey.com/s/ICPCNdelphi2>

To learn more and download instructions and background, go to [www.icpcn.org.uk](http://www.icpcn.org.uk)

