A message from our Chief Executive

As the ICPCN has continued to grow and develop through the past year, certain activities stand out as important milestones for children’s palliative care.

The World Health Assembly side-event on children’s palliative care in Geneva, proposed by Panama, Italy and Spain, and supported by a number of other countries, highlighted the importance of palliative care for children throughout the world. The attendance of Dr Margaret Chan, Director-General of the World Health Organisation, as well as Assistant Director-General Kieny and Assistant –Director-General Chestinov, was evidence of their support for our vision of a world where every child has access to palliative care.

ICPCN is active in all regions of the world
As a global action network, as well as a global children’s palliative care resource, we have been active in all regions of the world. In the Asia-Pacific region we presented a workshop in Taipei; taught in India, Malaysia and Indonesia; and presented at conferences in India and Indonesia. In Africa we continued with development work in Malawi; taught in Swaziland and presented at conferences in Uganda and South Africa. Our participation in Europe involved the EAPC Conference in Copenhagen; partnering with Dr Richard Hain and Cardiff University for their bi-annual Conference; helping Ukraine to develop children’s palliative care and participating in Rome in the development of the Charter for Religions Together for Children’s Palliative Care.

Representing children on the WHO Ad Hoc Technical Advisory Group for palliative and long-term care, I was fortunate to attend two meetings of this group and take part in the Global Colloquium on Palliative Care held in Dublin.

Latin-America is often overlooked, yet has some excellent programmes for children. We decided to hold our second conference in Argentina to highlight the wonderful work being done in the region, to raise the profile of children’s palliative care, and to support development across the region. To this end we visited Argentina to meet with the Argentine Paediatricians Association, UNICEF and the Argentine Palliative Care Association, all of whom agreed to support our conference, to be headed by Dr Rut Kiman from the ICPCN Board of Trustees.

It was important to be part of a palliative care advocacy discussion in New York, arranged by the Open Society Foundations, where we met and planned to work even more collaboratively with other global palliative care organisations.

Our mission to reach every child is facilitated through our global partnerships, communication, education, research and advocacy.

E-hospice, social media and our website reach so many people across the world and we frequently receive requests to assist with patients, clinical placements,
educational opportunities and information. ICPCN tweetchats have covered a variety of subjects; and our Hats on for CPC awareness event led to thousands of wonderful hats being worn in many different places, to honour children with life-limiting conditions.

**E-learning**

Our e-learning has now been completed by over 1000 people in 115 countries. We believe that education is essential to development, and complement the e-learning with numerous workshops in many different countries.

This past year we were able to build on the methodology we developed with UNICEF to provide a global estimate of over 21 million children who would benefit from palliative care – including over 8 million who require specialised palliative care.

Advocacy is ongoing through our own activities and in partnership with other advocacy groups. Our Global Ambassadors and Champions are our partners in advocacy and we welcome all they do to raise awareness and share our messages. While much is happening we are still far from reaching anywhere near these children, most of whom live in low and middle-income countries.

The only way we will protect the right of children to have access to palliative care is to continue to advocate and to educate; to share information and resources; and to collaborate with other organisations; and we are delighted to have built relationships with a number of different groups who now include palliative care in their strategies.

We are extremely grateful to our donors, especially the True Colours Trust, Monument Trust and Open Society Foundations; and to our active network members who share our vision.

Joan Marston
Chief Executive
Our year in review...

April 2015
- The ICPCN NOW Campaign is officially launched at the Asia Pacific Hospice Conference in Taipei.
- ICPCN and the Worldwide Hospice Palliative Care Alliance (WHPCA) submit a statement to UNAIDS as part of the consultation on the UNAIDS 2016–2021 Strategy, calling on UNAIDS to include palliative care as an essential component of care and support for children and adults at regional and global levels.
- Lucy Watts appointed as ICPCN’s first Global Youth Ambassador
- ICPCN holds its first Tweetchat with Joan Marston, Lucy Watts, Micheline Etkin and Dianne Gray as guests.
- ICPCN hosts pre-conference workshop on children’s palliative care at the Asia Pacific Hospice Conference in Taipei.
- Little Stars Feature film Premiere shown at the Asia Pacific Hospice Conference held in Taipei.
- Richard Newton, TV Journalist and ICPCN Champion, runs the London Marathon to raise funds for the organisation.
- ICPCN CEO (Joan Marston) interviewed on South Africa television regarding the WHA Side Event in Geneva on Children’s Palliative Care.

May 2015
- ICPCN receives a letter of support from the Vatican in which Pope Francis encourages those within the organisation and assures ICPCN of his prayers and blessings on our endeavours for the success of the NOW Campaign.
- ICPCN organises a successful Side Event at the 68th World Health Assembly in Geneva. Attended by over 90 delegates including a surprise visit by Dr Margaret Chan, Director General of the WHO.
- ICPCN staff present papers at the World Congress of the European Association of Palliative Care conference in Copenhagen.
- ICPCN CEO (Joan Marston) attended a meeting of the WHO Technical Advisory Group as the invited representative for Children’s Palliative Care.
- ICPCN CEO (Joan Marston) travelled to the Ukraine to support the development of Children’s Palliative Care and to provide training.

June 2015
- ICPCN appoints Cateline Khoo and Marquardt Petersen as Champions.
- ICPCN research reveals global need for children’s palliative care to be over 21 million children
- ICPCN launches ‘Going Global’ campaign to encourage partnerships between children’s palliative care services across the globe
- ICPCN’s elearning launched in Dutch and first students complete modules in this language

July 2015
- ICPCN collaborates with Dr Richard Hain and the Cardiff University to present the 7th International Cardiff Conference on Paediatric Palliative Care from 8 - 10 July 2015. The conference theme: ‘Medicine and Compassion: Tool for the Task...Or Dangerous Distraction?’
- In honour of Mandela Day, ICPCN organises a ‘Meet and Greet’ for children from the Paediatric Oncology Centre at Chittagong Medical College Hospital and the Proteas - South Africa’s national cricket team in Chittagong.
- Little Stars feature film selected for viewing at the Massachusetts Independent Film Festival
August 2015
- Publication in BMC Palliative Care of results of Delphi study, undertaken on behalf of ICPCN, list priorities for research in children’s palliative care.
- ICPCN puts out a call for abstracts for the 2nd International ICPCN conference to take place in Buenos Aires, Argentina
- ICPCN hosts second Tweetchat with guest Dr Stefan Friedrichsdorf speaking on pain management in children
- ICPCN supports the Palliative Care Association of Uganda’s conference in Kampala.

September 2015
- With input from ICPCN, Open Society Foundations publish a four page public health fact sheet on children’s palliative care and human rights.
- ICPCN provided training in Children’s Palliative Care in Malaysia

October 2015
- ICPCN holds its second ‘Hats on for Children’s Palliative care’ (#Hatson4CPC) campaign with a growing number of participants from around the globe.
- ICPCN CEO (Joan Marston) participates in the first Paediatric Palliative Care conference held in Lisbon, Portugal.
- World Hospice and Palliative Care Day sheds light on “Hidden lives, Hidden patients” with a strong focus on children as hidden patients.
- ICPCN co-publishes report with World Hospice Palliative Care Alliance on “Hidden Lives, Hidden Patients”.
- ICPCN participate in the Global Colloquium on Palliative Care held in Dublin, Ireland and co-sponsored by the World Health Organization.

November 2015
- ICPCN holds the first of two weeks of training on children’s palliative care for doctors, nurses and allied health professionals in Mbabane as part of an OSISA funded project to develop children’s palliative care in Swaziland.
- ICPCN provides a week of training on children’s palliative care for doctors, nurses and allied health professionals in Malawi as part of an OSISA funded project to develop children’s palliative care in Malawi.
- ICPCN attends closed workshop held in Rome to discuss religion and children’s palliative care and is represented at the launch of the “World Religion Charter for Children’s Palliative Care”.
- ICPCN launches a project “Bringing Children’s Palliative Care to Bangladesh” on the UK GlobalGiving Winter Gateway challenge to raise funds to develop CPC in Bangladesh.
- ICPCN supports the first symposium and training workshop on paediatric palliative care held in Bangladesh
- The first 7 students graduate from CPC Diploma course at Mildmay, Uganda. The development of this diploma course was supported by a project lead by the ICPCN with ICPCN’s Director of Education and Research as an external examiner.
- ICPCN CEO (Joan Marston) attended a meeting of the WHO Technical Advisory Group as the invited representative for Children’s Palliative Care.

December 2015
- Latin American actor, Roberto Manrique, is named as a global ambassador for ICPCN.
- ICPCN’s Director of Education and Research, Prof Julia Downing, gives a radio interview on recently published research on ‘Children’s Palliative care in low and middle income countries.’
- ICPCN releases a short video to explain and ask for support for the ICPCN NOW campaign.
• ICPCN places 4th in the Global Giving Winter Gateway Challenge to raise funds for the development of CPC in Bangladesh.
• ICPCN CEO (Joan Marston) travelled to the Ukraine to support the development of Children’s Palliative Care and to provide training.

January 2016
• ICPCN’s Global Youth Ambassador, Lucy Watts, is appointed as a Member of the Order of the British Empire in the Queen’s New Year’s Honours List 2016 for her services to young people with disabilities.
• ICPCN CEO (Joan Marston) presented at the PeriAsian Perinatal Conference in Indonesia
• ICPCN CEO (Joan Marston) provided training for a group of Indonesian Paediatric Oncologists together with a team from Cincinnati Children’s Hospital and Rachel House Children’s Hospice

February 2016
• ICPCN conducts a ‘Training of Trainers’ course for those who have completed the ‘Introduction to Children’s Palliative Care’ course in Swaziland.
• ICPCN hosts its 3rd Tweetchat on ‘Transition in children’s palliative care’ with guest Tweeters Lizzie Chambers and ICPCN’s CEO, Joan Marston

March 2016
• ICPCN works with leading health professionals in Swaziland adapting training materials and developing guidelines on children’s palliative care for that country.
• In response to the spread of the Zika virus and its effects, ICPCN publishes information on palliative care for babies and children with microcephaly and similar neurological birth anomalies.
• ICPCN’s Director of Education and Research, Prof Julia Downing, featured in a publication on ‘Women as Change Agents in Oncology’ launched on International Women’s Day.
Our year in pictures...
As a network, ICPCN is committed to keeping our members connected and informed. We are the only global children’s palliative care resource hub with membership in all regions of the world and in over one hundred countries worldwide. We keep our members informed through our website, the International Children’s edition of ehospice, our social media pages, regular blogs and our regular electronic news bulletins. Queries via the website are normally responded to within 24 hours and the ICPCN has been instrumental in connecting people and organisations across the world for training, mentoring, interning and experiential learning opportunities.

The ICPCN Website
Our website is central to the role of the organisation and provides updated and relevant information on children’s palliative care, research, global trends and provides a calendar of conference, workshops, study days and training opportunities related to the field. The resources section links to a number of useful resources including some in languages other than English. In this reporting period our website received 40,304 visits from 29,910 people in 185 countries. We received and responded to 46 requests for assistance via our website enabling us to connect people to the resources they needed, to other services they were looking for, or supplying the required information.

ehospice
The International Children’s edition of ehospice, edited by ICPCN, has a readership of over 10,000 people and endeavours to cover a wide spectrum of news topics from around the world that would be of interest to people who work in the field. ehospice also provides a platform for the advertising of job opportunities and the promotion of events and products that would be of interest to the readership.

News Bulletins
Our monthly news bulletins are sent via email to our membership and give an overview of what has been happening within the organisation and provide links to relevant pages on our website or articles on ehospice. They keep our members informed of events, news, campaigns and organisational updates.

Membership
ICPCN membership spans over 100 countries and on 31 March 2016 stood at 337 organisations and 1,384 individuals. Mapping where our members are in the world and which of the organisation provides some level of children’s palliative care assists us in staying informed of the development of services and enables us to put members from different parts of the globe in touch with one another when this is required. It also indicates the gaps in provision that need to be addressed.
The ICPCN NOW Campaign
The communications team was very involved in the dissemination of information related to the ICPCN NOW campaign, celebrating the ICPCN’s ten year anniversary. Work done included producing brochures, posters, banners and all media and marketing packs for the campaign. Channels used to raise awareness included all our social media platforms, children’s palliative care conferences in Rome and Cardiff and news bulletins in order to keep members informed of activities and events related to the NOW Campaign. While it is challenging to measure the impact of the campaign, the communication team worked hard to raise awareness of the work of ICPCN and of all campaign activities.

NOW Campaign Video
With our NOW campaign in full swing we approached the Durban University of Technology to help with the making of a video. They assigned the project of creating a campaign video to final year student Sphiwe Mngqiti. After much planning, and a day full of interviews, Sphiwe delivered a professional, fun and informative video that showed the many misconceptions about children’s palliative care. This video can be found on our website and our YouTube channel.

Little Stars Films
Throughout the past year ICPCN has worked in collaboration with the award-winning production team at Moonshine Movies firstly to connect them to services around the world for filming opportunities and then to promote the Little Stars series of short films and the full length feature film. These films document the surprisingly life-affirming stories of young people around the world living with life-limiting illnesses captured in 9 countries – the USA, South Africa, India, Australia, Malaysia, Italy, Jordan, the UK and Russia.

The Little Stars feature film, a 52 minute film produced by Mike Hill and Sue Collins of Moonshine Movies and is presented by acclaimed British actor David Suchet. The transparency, insight and emotional honesty of this documentary has left a lasting impression on all those who have seen it.

The premier of the Little Stars film was arranged by ICPCN and took place on 30 April at the 2015 Asia Pacific Hospice Conference, at the Taipei International Convention Centre. The ICPCN collaborated with Umduduzi Hospice Care for Children for the first screening of the feature film in South Africa. This took place on Saturday 3 October 2015, at Durban Girls College.

Social Media
Over the past year the ICPCN has provided timely and informative updates on news, research and events through our social media platforms. We are currently on Facebook, Twitter, Instagram and YouTube. We have seen an increase in following across all social networks largely due to our daily interactive and resourceful posts. We pride ourselves in being a central hub for children’s palliative care globally and our social networks have allowed us to share and reach more people from all corners of the globe.

We have run a number of successful social media campaigns including #nowcampaign, #KnowICPCN and #Hatson4CPC. These campaigns have not only
educated followers on our work, but they have also assisted in raising much needed awareness through fun and interactive activities like taking a selfie with a fun hat in honour of children’s palliative care!

As a part of our important role of sharing information we have hosted regular tweetchats discussing various topics in children’s palliative care. During these sessions we invite experts or ‘guest tweeters’ to discuss a range of topics from pain management, spirituality in children and children’s palliative care at a global level. Our tweetchats have proved to be beneficial as they provide an informal platform for our followers to ask and engage with experts. A participant said, “thank you to the ICPCN for organising this brilliant session. It’s great for us beginners to learn from the experts. More people should join these chats!”

Over the past year we have also extended our social media to include a blog on our website. Guest bloggers regularly send us personal, intimate and emotional stories that deeply resonate with our following. In the future we hope to see an increase and more participation from our followers across social media.

67 Minutes for Mandela Day
In July, Cricket South Africa approached the ICPCN with a request to spend their 67 minutes of service for Mandela Day with children with palliative care needs. Given that the South African national cricket team would be in Bangladesh playing at that time, we set up a ‘meet and greet’. Eighteen children with various life-limiting conditions from the Paediatric Oncology Centre at Chittagong Medical College Hospital in Chittagong, under the care of Dr Abdul Karim, joined the South African cricket players for an hour of fun in the sun. The players met the children, signed cricket bat’s and threw around a ball with the children that were well enough. This event was well covered by media in Bangladesh and South Africa and proved to be a wonderful opportunity to raise awareness of children’s palliative care and the work of the ICPCN. As a direct result of this awareness raising event, the ICPCN has since partnered with World Child Cancer to develop children’s palliative care in Bangladesh, using money raised through participation in the Global Giving Summer Challenge.

Global Giving Gateway Challenge
Communication played a pivotal role in ICPCN’s participation in the Global Giving Gateway Challenge during the months of July and August 2015. The campaign focused on raising funds to train 20 nurses and 10 doctors in children’s palliative care in Chittagong. Information provided to potential funders showed the need for children’s palliative care in Bangladesh with only 2 doctors at the time providing children’s palliative care in a country of 55 million children. Through dedicated reporting and funding requests sent out through all media and marketing channels, ICPCN was able to reach its £2,500 goal to become a permanent Global Giving Partner in both the United Kingdom and the USA. ICPCN won 4th place overall in the challenge.

VEGA NPO Winner for ‘Brand Challenge’ 2015
The ICPCN had the privilege of being selected as the 2015 NPO winner of the Durban VEGA School’s ‘Brand Challenge’. VEGA is a South African university specialising in marketing and branding and holds an annual competition for corporates and charities to be given ideas on revamping a brand. As winners, the ICPCN had three groups of final year students conducting research and giving recommendations to improve the ICPCN brand. Many ideas and events were suggested with full step by step guidelines and the
necessary materials. The ICPCN hopes to put some of the innovative ideas to use in the future.

**Hats on for children’s palliative care**

We held another very successful “Hats On 4 CPC” awareness raising event on Friday 2 October 2015. Resources were developed in six languages and included posters, hat templates, brochures and media releases.

ICPCN “Hats On 4 CPC” is an awareness and fund-raising campaign that the ICPCN has developed and promoted for the past two years. On this day people from around the world are encouraged to wear a hat to school or to work, take a photo wearing a fun hat, in honour of the different hats of the carers of children with palliative care needs, post on social media and hashtag #Hatson4CPC. Alternatively people are encouraged to buy a sticker and wear a hat to school/work or to host their own ‘Hats on for children’s palliative care’ event, and donate funds to the ICPCN or their local children’s hospice. From India all the way to Buenos Aires we received wonderful support from our members across the globe. Our hope is that ‘Hats On 4 CPC’ will grow and develop into a fixed annual awareness and fund-raising day for the ICPCN.

**World Day Report**

The theme for World Hospice and Palliative Care Day 2015 namely, *Hidden Lives, Hidden Patients*, was chosen to coincide with the ICPCN’s 10 year anniversary and NOW Campaign. It highlighted numerous groups of people regularly overlooked within health systems and palliative care providers. In partnership with the Worldwide Hospice Palliative Care Alliance a 30 page report was produced; collated and edited by ICPCN Director of Education and Research, Prof Julia Downing and designed by ICPCN Director of Communication, Sue Boucher. The report documents stories from hidden communities around the world with a particular focus on the hidden lives of many children with life-limiting conditions. It can be downloaded from both the ICPCN and WHPCA websites.

**2nd ICPCN Conference - Buenos Aires 2016**

The communication team has been hard at work developing advertising and awareness raising materials for the 2nd ICPCN Conference to be held in Buenos Aires in May 2016. These have been shared on all electronic and social media platforms as well as printed materials at conferences and events related to paediatrics and palliative care.
Advocacy

It has been a busy year of advocacy for the organisation with the highlight being the Side Event held at the 68th World Health Assembly in Geneva in May 2015 that was organised by the ICPCN. Much has been achieved in this time period, but there is still a lot of work that lies ahead in order to advocate for the 21 million children in the world who would benefit from palliative care.

WHA Side Event
On the 25th May in 2015 ICPCN held very successful a side event on children’s palliative care at the 68th World Health Assembly in Geneva. The aim of this event was to highlight the need for palliative care for children with life limiting and life threatening illnesses globally. The event was titled “Implementing the WHA Resolution on Palliative Care”. It was a resounding success with over 90 delegates in attendance. The panel included speakers from various countries who addressed important aspects of children’s palliative care, these being:

1. The global need for children’s palliative care - Joan Marston, ICPCN Chief Executive (South Africa)
2. Integrating children’s palliative care into the main health system in Belarus - Anna Garchakova, Director, Belarus Children’s Hospice (Belarus)
3. Developing a national policy for children’s palliative care in Italy - Sylvia Lefebvre D’Ovidio Director, Fondazione Maruzza (Italy)
4. Improving access to pain medicines for children in India - Dr M. Rajagopal. Founder/Chairman, Pallium India (India)
5. Pain in children - Prof. Anne-Sylvie-Ramalet, Associate Professor, University of Lausanne, IASP (Switzerland)

The highlight of the event was the unexpected attendance by the WHO Director General, Dr Margaret Chan. In a short speech to delegates, she confirmed the importance of children’s palliative care and commended the non profit sector who are doing work in this field, saying “this is a very important subject”.

Introductory remarks were provided by WHO Director Generals, these being Dr Oleg Chestnov and Dr Marie-Paule Kieney and was closed by the Panamanian Ambassador, His Excellency Mr Giancarlo Soler Torrijos. Following this event a working relationship has been developed between the WHO and ICPCN and it has been agreed the two organisations will collaborate on specified projects to develop and strengthen children’s palliative care around the globe. Mrs Joan Marston, Chief Executive of ICPCN, is the civil society lead person in the implementation of the WHA Resolution on Palliative Care.

Regional Inter-Agency Task Team for Children with HIV/AIDS
Busi Nkosi, ICPCN’s Director of Advocacy, is a member of the Regional Inter-Agency Task Team for children with HIV/AIDS in Eastern and Southern Africa (RIATT-ESA) and is the chair of its Care and Support Working Group. As a result of this membership, she has been able to include palliative care in all the documents that are developed for children with HIV/AIDS in Eastern and Southern Africa. References to children’s palliative care have also been included in international documents that have been referred to RIATT-ESA. Due to the fact that RIATT-ESA is a network of children’s
organisations, it has been possible to introduce and create awareness of children’s palliative care across the network.

**Hats On for CPC**
A function to celebrate Hats On for CPC day was held on Friday 2 October 2015 at the Wits Centre of Palliative Care Excellence, Chris Hani Baragwanath Hospital in South Africa. The function was attended by nurses, doctors and social workers who responded with interest to the talk given on children’s palliative care. The success of the campaign was also marked by the radio and television interviews granted by the South African Broadcasting Corporation, which was followed by a number of enquiries for more information on children’s palliative care and the location of hospices around South Africa.

**Global Ambassadors and Champions**
Over the past year ICPCN was thrilled to announce the appointment of Roberto Manrique as a Global Ambassador for the network. Born in Ecuador, Roberto is a sought after television and stage actor in Latin America and is also extremely popular with the Hispanic audience in the US. He joins our other global ambassador, Micheline Etkin, in raising awareness of children’s palliative care issues within their own large following.

In April 2015, ICPCN appointed Lucy Watts as our first Global Youth Ambassador. Lucy is a young person living with Ehlers Danlos (ED) Syndrome, a condition that affects the connective tissue, and causes organ failure. She is wheelchair bound and spends most of her time in bed but is determined to make a difference in the lives of others. Lucy lives in England.

**Advocacy to Nurses**
The Democratic Nurses Organisation of South Africa (DENOSA) produces a monthly magazine for nurses titled *Nursing Update*. To raise awareness of children’s palliative care in the South African nursing profession, a series of articles were submitted for publishing in the magazine. It was rewarding to receive a positive response by the nurses to these articles at the DENOSA conference in Johannesburg in February 2015.

As part of the South African Palliative Care Alliance, Busi Nkosi has assisted the South African Department of Health to develop a policy for palliative care in South Africa, thus implementing the WHA Resolution: *Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA67.19)*. The policy is currently in draft form.

**Key Messages**
The advocacy working group developed key messages to encapsulate what is needed to achieve a level of palliative care for children. These messages have been translated into French, Spanish, Italian, Russian, German, Portuguese and Kiswahili. More translation into other languages is still taking place in order for the messages to be understood throughout the world. A strategic plan to implement the messages in a coherent manner across the world has been developed.

**Key messages**
1. Access to good health care, including palliative care, is every child’s right.
2. Good pain and symptom management, making use of paediatric formulations when needed, is every child’s right.
3. Universal Health Coverage must include palliative care for children by skilled health care workers.

Video Messages of Support
In preparation for the 2nd ICPCN conference to take place in May 2016, a message of support was sought from Archbishop Desmond Emeritus Tutu, and this was obtained in the form of a short video in which he thanks members of the network for the work they do for children.

Children’s Palliative Care in Swaziland
In a bid to develop CPC in Swaziland and scale up CPC in Malawi, ICPCN solicited funds from the Open Society Initiative of Southern Africa. These funds assisted the government of Swaziland to train health care workers in CPC, develop national CPC Guidelines and Curriculum. Swaziland is now ready to roll out CPC throughout the country. These funds also enabled the government of Malawi to train health care workers and extend the CPC to the district levels, previously only limited to central hospitals.

Busi Nkosi
Director of Advocacy
ICPCN Annual Report 2016

WHA Side Event

ICPCN advocating for children’s palliative care at the World Health Assembly 2015
During the year 463 individuals participated in the ICPCN e-learning programme from all around the world. (33% Europe, 8% Latin America, 3% North America, 4% Oceania, 21% Asia, 23% SS Africa, 8% Middle East and North Africa).

Courses

Six e-learning courses were available, free of charge, via the ICPCN e-learning website (www.elearnicpcn.org) on different aspects of children’s palliative care. These were:

1. Introduction to Children’s Palliative Care
2. Communication and emotional issues
3. Pain assessment and management
4. Child development and play
5. End-of-life care
6. Grief and bereavement

Three more e-learning courses have been developed and are in the process of being uploaded:

- Management of symptoms other than pain
- Introduction to research
- Perinatal and neonatal palliative care

The e-learning courses are now available in eight languages - English, French, Russian, Serbian, Spanish, Portuguese, Mandarin and Dutch with Hindi soon to be added. As validation of the value of the ICPCN e-learning programmes they were endorsed by the University of South Wales and ICPCN has continued to partner with Stitching Pal, the national children’s palliative care foundation in the Netherlands, to produce the e-learning courses in Dutch.
Face to Face Training
Face-to-face training in children’s palliative care was carried out by ICPCN staff in a variety of countries including Bangladesh, Ukraine, India, the Czech Republic, South Africa, Malaysia and Swaziland. Alongside these courses, ICPCN was involved in organising and presenting at pre-conference workshops on children’s palliative care at palliative care conferences held in Taiwan, India and Malaysia.
Other educational activities included: external examining for the Diploma in Children’s Palliative Care run by Mildmay, Uganda; External examining for several MPhil’s and PhD’s on related topics, working on the process of building on existing programmes to develop an online diploma/ degree in children’s palliative care.

Evaluation of Training
An anonymous online survey was administered via SurveyMonkey, consisting of 28 questions, 14 demographic, 11 relating to the training, and 3 to ICPCN membership. All participants who had attended ICPCN courses, and e-learning courses, were invited, via email, to take part.

100 participants completed the survey, 48% from sub-Saharan Africa, 42% nurses, 36% doctors. 53% had worked in CPC for between 1-5 years. 55% of participants had completed an e-learning course, 34% undertook a clinical placement and 59% had completed the training at least six-months prior to completion.

82% of e-learning participants found the courses clear and understandable, 80% found them useful and 84% rated the course highly. Face-to-face training was rated higher with 94%, 91% and 94% respectively. 74% of all participants said their knowledge had improved, 73% their skills, 73% their attitude and 61% said it had changed their clinical practice. Participants verbalised changes in practice, confidence, attitude and care.

Thus both the e-learning and face-to-face training provided by ICPCN are having an impact on the provision of CPC, and a variety of training methods can be employed.

RESEARCH
The results of ICPCN’s Delphi study to identify priorities for global research into children’s palliative care were published and the results disseminated. The results
of this have helped to focus ICPCNs research activities and planning for future research is in line with the identified priorities. Following completion of the study undertaken in conjunction with UNICEF to look at the need for children’s palliative care in three African countries, the study has been extended to other countries covering a range of high, middle and low income countries, and a global estimate has been calculated of over 21 million children worldwide who will benefit annually from a palliative care approach, with more than 8 million children needing specialized palliative care worldwide. ICPCN partnered with different organisations to do this work including, UNICEF, True Colours Trust, EMMS International, the Russian Children’s Palliative Care Foundation and Open Society Foundation.

A study has commenced in conjunction with Global Partners in Care and the team at Akron Children’s Hospital in the USA, looking at the ‘Understanding of Death and Dying in Children with Life-limiting illnesses and their siblings.’ This study came out of the African Palliative Care Research Network workshop prior to the last APCA conference in Johannesburg. At this workshop the group interested in research in children’s palliative care brainstormed different topics for future research and highlighted the need to explore children’s understanding of death and dying – and so brainstormed this study. Importantly this was also the top priority for research as identified in the Delphi study. Thus when approached by the team in the USA it was agreed that we would develop the protocol further and start looking at children’s understanding of death and dying in South Africa, USA and Haiti. A protocol will also be developed that can be used in other countries to explore similar issues. Data collection has commenced in Haiti and the USA and is soon to commence in South Africa.

A follow on from the survey undertaken at the ICPCN conference in India on the WHO pain guidelines, was carried out in Uganda in conjunction with Penn State University, exploring the use of the two and three step ladder in children’s palliative care. Data was collected and is currently being analysed. An online evaluation of the impact of the ICPCN training programmes was undertaken and analysed and implications for the ICPCN education strategy reviewed. A paper on the development of the APCA African C-POS has been submitted for publication, and plans are underway to develop a similar scale in the UK, and several countries have been in touch with the possibility of adapting and translating.

**Dissemination**

Ten papers were published by ICPCN on key aspects of children’s palliative care including: the role of play, palliative care in complex humanitarian crisis, children’s palliative care in low and middle income countries, priorities for global research, children with HIV/AIDS, outcome measurement, research round up and pain management. The publication for World Hospice and Palliative Care Day – Hidden Lives, Hidden Patients, also had a strong child focus with ICPCN as a co-publisher of the report. The papers were published in a wide variety of journals including the IJPN, the Lancet, BMC Palliative Care, Palliative Medicine and Pain Management. Chapters have also been included in several books e.g. The Role of Play in Children’s Health and Development and Palliative en Ninos y Adolescentes.

ICPCN are regularly invited to present at key national, regional and international conferences – giving over 15 presentations within the year on a wide variety
of topics. Conferences attended included the 11th Asia Pacific Palliative Care Conference, the 14th World Congress of the European Association of Palliative Care, the World Cancer Leaders Summit, the 47th Congress of the International Society of Paediatric Oncology, the 7th International Cardiff Conference on Paediatric Palliative Care, Global Colloquium on Palliative Care in Ireland, Global perspectives for palliative care integration and health systems strengthening in Edinburgh, the Indian Association of Palliative Care Conference, the Palliative Care Association of Uganda conference, Palliative Care Works conference and the HPCA conference, amongst others.

ICPCN staff were also involved in providing technical assistance for various organisations and attending key meetings e.g. the WHO TAG, UN Committees, IAHPC, PCRS etc. taking advantage of networking opportunities and ensuring that we have a global impact. Editing the International Children’s Edition of e-hospice is also an essential method of dissemination, as are the different campaigns that ICPCN are involved in such as the Only Now Campaign.

Following the success of the first ICPCN conference in Mumbai, a second conference was planned for Buenos Aires in May 2016. Thus work was carried out throughout the year on the preparation and planning for the conference. ICPCN were also partners in organising the 7th International Cardiff Conference on Paediatric Palliative Care held in July 2015.

Prof. Julia Downing
Director of Research and Education
Finance

ICPCN has managed all grants and funding efficiently and within budget. Income for the year was £241,332 and comprised mainly grants from True Colours Trust, Monument Trust, the Open Society Foundation and the Open Society Initiative of Southern Africa. Expenditure on various projects amounted to £255,206.

At the financial year end, which was 29th February 2016, the free reserves of the charity amounted to £22,433. This is equivalent to just over one month’s expenditure, and ICPCN plans to invest staff time in fundraising over the coming year in order to ensure the charity’s sustainability in the longer term.

Barbara Steel
Admin and Finance Manager

A breakdown of income and expenses for the financial year March 2015 to February 2016 is shown in the charts below:

### Income

<table>
<thead>
<tr>
<th>FUNDER</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>True Colours Trust &amp; Monument Trust</td>
<td>£114 802</td>
</tr>
<tr>
<td>Open Society Foundation</td>
<td>£84 603</td>
</tr>
<tr>
<td>Open Society Initiative for Southern Africa</td>
<td>£26 458</td>
</tr>
<tr>
<td>General Fund - unrestricted</td>
<td>£15 469</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£241 332</strong></td>
</tr>
</tbody>
</table>

![ICPCN Income Resources 2016](image)
### Expenditure: Direct costs

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governance costs</td>
<td>£3 309</td>
</tr>
<tr>
<td>UK Travel</td>
<td>£1 982</td>
</tr>
<tr>
<td>Travel in Africa</td>
<td>£6 442</td>
</tr>
<tr>
<td>International travel</td>
<td>£11 345</td>
</tr>
<tr>
<td>Project Costs</td>
<td>£43 528</td>
</tr>
<tr>
<td>Conference Costs</td>
<td>£2 650</td>
</tr>
<tr>
<td>Salaries &amp; Wages</td>
<td>£14 718</td>
</tr>
<tr>
<td>Consultancy Costs</td>
<td>£44 667</td>
</tr>
<tr>
<td>Consultancy Expenses</td>
<td>£7 667</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£136 308</strong></td>
</tr>
</tbody>
</table>

### Expenditure: Support Costs

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admin &amp; Management Fees</td>
<td>£763</td>
</tr>
<tr>
<td>Postage, Printing &amp; Stationery</td>
<td>£1 689</td>
</tr>
<tr>
<td>IT Expenses</td>
<td>£854</td>
</tr>
<tr>
<td>Telephone Costs</td>
<td>£4 914</td>
</tr>
<tr>
<td>Consultancy Costs</td>
<td>£5 882</td>
</tr>
<tr>
<td>Bank Charges</td>
<td>£700</td>
</tr>
<tr>
<td>Website Development Costs</td>
<td>£907</td>
</tr>
<tr>
<td>Training Costs</td>
<td>£2 908</td>
</tr>
<tr>
<td>Accounting Fees</td>
<td>£44</td>
</tr>
<tr>
<td>Interest Paid</td>
<td>£172</td>
</tr>
<tr>
<td>Insurance</td>
<td>£533</td>
</tr>
<tr>
<td>Staff Expenses</td>
<td>£64</td>
</tr>
<tr>
<td>Marketing, Advertising, Promotions</td>
<td>£1 397</td>
</tr>
<tr>
<td>Development &amp; Printing of Educational Materials</td>
<td>£43</td>
</tr>
<tr>
<td>Foreign Exchange Adjustments</td>
<td>£6 703</td>
</tr>
<tr>
<td>Salaries &amp; Wages</td>
<td>£90 028</td>
</tr>
<tr>
<td>Depreciation</td>
<td>£1 297</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£118 898</strong></td>
</tr>
</tbody>
</table>

### Summary

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff costs</td>
<td>£104 746</td>
</tr>
<tr>
<td>Travel costs</td>
<td>£19 769</td>
</tr>
<tr>
<td>Direct project costs</td>
<td>£46 221</td>
</tr>
<tr>
<td>Office &amp; admin costs</td>
<td>£22 945</td>
</tr>
<tr>
<td>Consultancy Costs</td>
<td>£58 216</td>
</tr>
<tr>
<td>Governance Costs</td>
<td>£3 309</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£255 206</strong></td>
</tr>
</tbody>
</table>
Board of Trustees

We are thankful for the support and direction voluntarily given by our global Board of Trustees who uphold the work and mission of ICPCN wherever they are in the world. They are:

- Dr/Prof Maryann Muckaden (Chair) - India
- Ms Sabine Kraft (Vice Chair) - Germany
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- Ms Sharon Baxter - Canada
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- Dr Rut Kiman - Argentina
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- Dr Marianne Phillips - Australia
- Dr Marli Roberson - Canada
- Mrs Joan Marston - Chief Executive (ex officio member)

Our Funders

Without the continued loyal support of a small group of funders, the ICPCN would not have achieved all that it has done over the past year. We would like to record our most sincere gratitude to the following funders:

- The True Colours Trust
- The Monument Trust
- Open Society Foundations
- Open Society Initiative of South Africa
- EMMS International