The past 11 years watching the ICPCN grow from the dream and vision of a few enthusiastic people to a truly global organisation that is recognized and respected for the achievements that have been made for children all over the world, has been immensely satisfying. Having staff, board members and active volunteers living in different countries, regions, time and language zones has been challenging; but the success of the 2nd ICPCN Conference in Buenos Aires in May was an indication of how we have successfully worked together as a team, despite the distances and challenges.

The 2nd ICPCN Conference
The Conference – Children’s Palliative Care NOW- carried through the theme of our 10 year anniversary, and was in itself a colourful and vibrant celebration in truly Latin style. This success was largely due to Dr Ruti Kiman working with her wonderful regional team who managed to obtain many donations in all kinds and forms, as well as support from all the important national and regional palliative care and paediatric organisations, from UNICEF and from the Argentine government. Listening to the different presentations and the Big Debate on euthanasia in children was an indication of the way the field is growing and developing – coming to maturity.

The ICPCN Board
May also saw a change in the leadership of the Board. Prof. Mary Ann Muckaden has been an active and dedicated Chair despite her many other responsibilities and it was due to her leadership that our project in Maharashtra was the success that it was. Sabine Kraft, our new Chair has been with the ICPCN almost from the beginning and has been a committed vice-chair for most of that time, so she brings with her a deep understanding of the organisation and its’ governance, and a renewed vision for the ICPCN. At the same time the Board expanded to include representation from more regions of the world and our first parent representative. The Board and creative, dedicated staff have worked together successfully, have become more friends than colleagues, and the direction of the ICPCN is in their collective safe hands.

Our loyal funders
The ICPCN “team” has always included our long-term donors, the True Colours Trust and the Open Society Foundations as, without their belief in the ICPCN, we would not have had the resources to achieve what has been achieved. The ICPCN is growing in collaboration with other international NGOs such as EMMS International, World Child Cancer, Childhood Cancer International, and others.

Staff
Leaving the ICPCN at the end of October was made easier by the knowledge that there is continuity of staff, strong leadership and the ongoing international collaboration that
makes all we do work effectively so that we are further along the path that reaches towards our vision of palliative care for all children.

Joan Marston

As I have taken up the role of Chief Executive of ICPCN, I do so with gratitude for all that Joan has done and achieved over the years as she has steered ICPCN initially as the Chair and then as the Chief Executive. She has done so much, not just for ICPCN but for children with life-limiting and life-threatening illnesses around the world. I am also excited and honoured to be taking on this role and to be steering ICPCN over the coming years. I believe in the work of ICPCN, in the work that we do, as an organisation, including our members, to promote and develop children’s palliative care around the world.

As we start the next phase of the life of ICPCN I am reminded that ICPCN CARES. That we work on these five key areas: Communication, Advocacy, Research, Education and Strategic Development. As we focus on these different activities it is clear that they are interlinked, and that we are often working in all five areas at once as we support the development of children’s palliative care. In thinking about our annual report, our activities, our staff, our members, stakeholders and friends, I am aware that without you all we would be unable to support the development of children’s palliative care around the world and we thank you for all that you are doing, often in very difficult circumstances, and we hope that ICPCN will be able to continue to support you, encourage you and inspire you in all that you are doing.

As we look back over the past year there have been many changes at ICPCN, but importantly there has also been much development in the field of children’s palliative care. It is exciting to see the changes, and although we still have a long way to go to ensure that all 21.6 million children who need it, have access to palliative care, we have come a long way in the last few years and we encourage you all to keep moving forwards, and doing what you can to improve the quality of life of children in need around the world.

Thus we celebrate all that has been done this past year and look forward in anticipation for what the next year will bring.

Prof. Julia Downing
Our year in review...

April 2016
• ICPCN participates in the launch of ‘A Really Practical Handbook of Children’s Palliative Care’ edited by Dr Justin Amery. The book is made available for download from the ICPCN website.
• ICPCN releases 3 key advocacy messages on World Health Day:
  1. Access to good health care, including palliative care, is every child’s rights.
  2. Every child should receive good pain and symptom management, making use of paediatric formulations when appropriate.
  3. Universal Health Coverage must include palliative care for children by skilled healthcare workers.
• Project to promote and develop children’s palliative care in Bangladesh is initiated by World Child Cancer with technical support from ICPCN.

May 2016
• Tweetchat held on the global need for CPC – Guest tweeters, Joan Marston and Prof Julia Downing
• Full day of pre-conference workshops held at the conference venue in Argentina
• Successful 2nd ICPCN Conference held in Buenos Aires, Argentina
• ICPCN Board of Trustees Annual Meeting
• Ms Sabine Kraft (Germany) takes over from Prof Maryanne Muckaden (India) as Chair of the ICPCN Board of Trustees
• ICPCN recognises Dr Rut Kiman, Dr Lisbeth Quasada, Dr Rosa Germ and Dr Eulalia Lascar with awards for their contribution to the development of children’s palliative care in South America.
• ICPCN launches the ‘Just One Thing’ campaign to raise funds for the education programme and day to day expenses of the ICPCN

June 2016
• ICPCN supports a 3 day of intensive training on CPC in Dhaka, Bangladesh. The training was attended by more than 85 paediatricians, palliative care physicians, nurses, pharmacists, palliative care assistants and social workers.
• ICPCN’s Global Youth Ambassador, Lucy Watts, is awarded a Member of the British Empire (MBE) by HRH Prince Charles at Buckingham Palace.

July 2016
• ICPCN welcomes new members to their Board of Trustees.
  Peter Ellis, Chief Executive of Richard House Children’s Hospice in the United Kingdom
  Lyn Gould, Director of Operations and CEO of Butterfly Children’s Hospices in China
  Dianne Gray, President of the Elisabeth Kübler-Ross Foundation and of Hospice and Healthcare Communications in the United States
  Paul Quilliam, Co-founder of Hummingbird House in Queensland, Australia
• Professor Julia Downing is awarded an Honorary Fellowship from Cardiff University
• Joan Marston was the international speaker at the International Pediatric Pain and Palliative Care Master Class held in Minneapolis under the leadership of Dr Stefan Friedrichsdorf.

August 2016
• ICPCN holds a workshop on CPC at the African Palliative Care Association (APCA) conference
ICPCN Annual Report 2017

held in Kampala, Uganda

- Joan Marston, ICPCN Chief Executive, is presented with a global achievement award for her work in developing CPC at the APCA Conference. The award is presented by Lucy Sainsbury, founder of the True Colours Trust, who have supported ICPCN from its inception.
- A 2-day ICPCN workshop on CPC for health and related professionals is presented at Mildmay Uganda. Prof. Maryann Muckaden, Immediate Past Chair of the Board of Trustees, participates along with other ICPCN staff members
- ICPCN presented at a Seminar in Cape Town organised by the national CPC network, PatchSA.

September 2016

- ICPCN Tweetchat held on ‘End-of-life’ conversations. Guest Tweeter was Lucy Watts
- ICPCN provides training materials and support for ‘Introduction to CPC’ training held in Vietnam. The training was attended by 50 local staff working in an orphanage in Ho Chi Minh City.
- Representing ICPCN Joan Marston presented at the 1st Austrian PPC Conference in Salzburg.

October 2016

- Prof Julia Downing represents ICPCN at a conference in Edinburgh ‘Palliative care: a global priority. Perspectives on integration and health systems strengthening’
- Successful 4th annual Hats On for CPC Day held on Friday 14 October to raise funds and awareness of the need for children’s palliative care around the world.
- Prof. Julia Downing visits Rachel House, an NGO pioneering children’s palliative care in Indonesia, to explore ways of intensifying collaboration so palliative care, still in its infancy in the country, keeps developing and becomes accessible for all children who need it.
- ICPCN participates in a 3-day workshop on CPC held in Kuala Lumpur, Malaysia. The workshop, run by Hospis Malaysia was attended by 72 participants from across Malaysia and Singapore.
- ICPCN introduces new e-learning course on perinatal palliative care suitable for health professionals and support workers involved in the delivery of care to infants and their families.
- At the end of this month, Joan Marston stepped down from her role as Chief Executive of ICPCN.
- Sabine Kraft attended the World Health Summit in Berlin, Germany as an ICPCN representative.
- Busi Nkosi attended a meeting with the Lesotho Ministry of Health to plan development of CPC in Lesotho.
- Representing ICPCN Joan Marston presents at a palliative care conference in Barcelona and at a Spirituality in Healthcare Conference in Pretoria, South Africa.

November 2016

- Professor Julia Downing takes over as Chief Executive of ICPCN.
- Joan Marston accepted the role of Global ICPCN Ambassador for ICPCN.
- Prof Julia Downing and Joan Marston represent ICPCN at the UICC World Cancer Congress in Paris.
- Joan Marston, past Chief Executive, is awarded the prestigious Vittorio Ventafridda Award at the opening ceremony of the Maruzza Foundation Global’s 3rd Paediatric Palliative Care Conference: A Global Gathering.
- Professor Julia Downing leads a workshop on Research in Children’s Palliative Care at the Rome Conference.

December 2016

- Professor Julia Downing represents ICPCN at the Salzburg Global Seminar on ‘Rethinking care toward the End-of-Life’
- First call for papers is made for the 8th PPC Cardiff Conference 2017 to be held in July 2017. ICPCN is partnering with the organisers of the conference.
January 2017
- ICPCN Board Member, Lyn Gould, receives an MBE for her services to the provision of palliative care to babies and infants in China.

February 2017
- Prof Julia Downing represents ICPCN at the Indian Association of Palliative Care Conference in Coimbatore, chairing a session on Taking care of children.
- Healthcare professionals in Lesotho trained in children’s palliative care by ICPCN. Under the auspices of the ICPCN and in collaboration with the Lesotho Ministry of Health (MoH) a week-long training of healthcare professionals in the principles of children’s palliative care took place in Maseru, the capital of Lesotho.
- ICPCN wins an award for Excellence in Palliative Care Development in the 2017 Social Care Awards supported by Global Health and Pharma (GHP)
- Sabine Kraft, Chair of ICPCN hosts a meeting in Berlin of key individuals from Eastern Europe working in CPC
- ICPCN participates in the first meeting of leaders and experts in CPC research to introduce Cochrane methods and the Cochrane review process to the CPC community.

March 2017
- Successful Tweetchat on ‘Pain in Children’ with Dr Christine Chambers and Dr Allen Finley.
- Prof Julia Downing represents ICPCN at a Royal College of Nursing Education conference in Cardiff.
Our year in pictures...
Communication & networking

ICPCN is the only global children’s palliative care network and we are committed to keeping our members connected and informed. Our growing membership come from all regions of the world and represent 124 countries worldwide. Members are kept informed through our website, the International Children’s edition of ehospice, our social media pages (Facebook, Twitter and Instagram), regular blogs and our monthly electronic news bulletins. Queries via the website are responded to within 24 hours and the ICPCN regularly connects professionals across the world for the purpose of research, training, mentoring, interning and experiential learning opportunities.

Membership
ICPCN membership spans over 124 countries. Organisations belonging to ICPCN can be found in the ICPCN Directory on our website. We have also added to our website a map of services providing palliative care to children, and update this map as services become known to us. This assists us to stay informed of the development of services worldwide and enables us to connect members and organisations across the globe, when this is required. It also indicates the gaps in provision needing to be addressed.

The ICPCN Website
Our website is the official window to the work we do and is regularly updated with relevant information on children’s palliative care research, news and global trends. It provides an up-to-date calendar of events which include conferences, 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.

ehospice
The International Children’s edition of ehospice, edited by ICPCN, has a readership of more than 11,200 people and covers a wide spectrum of news topics from around the world of interest to people who work in the field of children’s palliative care. 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
Regular e-bulletins are sent via email to our membership and give an overview of what has been happening within the organisation, provides links to relevant pages on our website or articles on ehospice.
2nd ICPCN Conference
Over the months leading up to the 2nd ICPCN Conference, held in Buenos Aires in May 2016, the Communications Team devoted much time and energy on producing materials to promote and facilitate the conference. Activities included the management of the conference website, in both English and Spanish and the development of marketing materials to encourage participation.

Design of conference banners, the programme, programme cover, name tags and abstract book was all done in-house and in both English and Spanish. Sessions and events that took place at the conference were highlighted on both the ICPCN website and via the international children’s edition of ehospice.

Post conference, all presentations were uploaded to the website in PDF format for download by participants and other interested parties. A report of the conference was published by ecancer in both English and Spanish.

Social Media
Over the past year, the ICPCN has continued to provide relevant and up-to-date information on children’s palliative care through our social media platforms. We have a social media presence on Facebook, Twitter, Instagram and YouTube and have seen an encouraging increase in following and engagement of posts over the past year. In our continued effort to impart information to followers, the ICPCN hosts regular tweetchats with experts in that particular field sharing and engaging with followers.

Tweetchats over the past year have covered a range of topics, including: children’s palliative care at an international level, transition from child to adult palliative care services, perinatal palliative care and pain in children. We plan to increase our reach through social media in 2017 through live streaming options such as Facebook Live and webinars.

In 2017 the ICPCN committed to running various themes across social media to share important information with followers.

In moving with the recent trend of video content, the ICPCN has developed a number of videos during the past year which highlight different campaigns and the important work we do. Videos have been uploaded on the ICPCN YouTube channel and shared extensively across social media.

Over the past year the ICPCN also published a number of relevant blog posts from parents, healthcare professionals and children’s palliative care advocates.

Hats on for children’s palliative care
Hats on 4 CPC, our annual initiative encourages people to wear a hat on the second Friday of October to raise awareness and funds for children’s palliative care. Social media followers take a photo of themselves in a hat and post this photo using the hashtag #Hatson4CPC.

Companies, organisations and schools are encouraged to take part in the campaign and make it their own by hosting a Hats on 4 CPC event and donating funds raised to the ICPCN
or their local children’s palliative care service. Last year was the 3rd year of running this campaign and we are pleased that it has grown from strength to strength. In 2016, Hats on 4 CPC events were held in over 30 countries, including Romania, Hong Kong, South Africa, Mexico, Canada and Germany. The ICPCN received substantial support on social media with the hashtag #Hatson4CPC receiving almost 5000 hits from across the world.

**Just One Thing**

At the 2nd ICPCN Conference held in Buenos Aires, the Just One Thing campaign was launched to encourage healthcare and allied professionals working in children’s palliative care, schools, companies and the general public to commit to performing an action that will benefit the over 21 million children with life-limiting and incurable conditions worldwide. The campaign was widely advertised through social media, at various conferences and children’s palliative care events. An easy to follow web page and campaign video were developed and as a result the ICPCN received a total of 158 commitments.
Advocacy

It was a busy and productive year developing and growing the Advocacy portfolio and ICPCN has been particularly busy on the African continent.

Global advocacy
ICPCN has a key role in advocating for children’s palliative care globally. As part of the advocacy group for the Worldwide Hospice and Palliative Care Alliance (WHPCA), ICPCN is involved in a co-ordinated advocacy campaigns to strengthen palliative care globally, both for adults and children. Activities under this have included working together on the annual World Palliative Care Day, the theme of which was ‘Living and Dying in Pain: It doesn’t have to happen’, working on position statements and advocacy materials for specific events e.g. the World Health Assembly, the UN high level meetings etc. ICPCN works closely with the bilateral organisations for example the UN with regards to the Inter-Agency Task Team (IATT) on HIV Care and Support and Social Protection, and the World Health Organization Technical Advisory Group (TAG) for palliative care. As part of the global voice, ICPCN represents the voice of the children and much of the work of ICPCN is linked to advocating for children’s palliative care around the world.

There are many examples of ICPCN’s advocacy activities around the world, some examples of which are as follows:

Swaziland
ICPCN was fortunate to receive a grant from OSISA to develop palliative care services for children in Swaziland. After training health professionals in 2015, it was necessary to develop documents that would support them in providing the service to children and their families. In consultation with relevant stakeholders, the following documents were produced:

- National Guidelines to guide the practice of the health workers
- Curriculum for training health workers in palliative care for children
- Two manuals for training in children’s palliative care, one for participants and one for facilitators.

These are to be distributed to all the regions in the country. In May 2017 trainers who were trained by ICPCN in 2016 will for the first time, train their peers using the above mentioned documents.

South Africa
ICPCN is also a member of the South African Palliative Care Alliance which drives the palliative care agenda in South Africa. The Advocacy Director sits in meetings of this Alliance which take place quarterly. This Alliance has achieved a big milestone for palliative care in South Africa, its steering committee has succeeded in drafting a National Policy for Palliative Care which was accepted by the National Health Council.

As part of the global campaign to promote CPC, a successful Hats On 4 CPC event was staged at Chris Hani Baragwanath Hospital in Johannesburg, South Africa in September 2016. All categories of health care workers learned, some for the first time, about CPC.
Ordinary public members who have benefitted from palliative care shared their experiences of caring for children with life limiting and life threatening illnesses. This event was a joint collaboration between ICPCN and Wits Palliative Care – Gauteng Centre of Excellence for Palliative Care which offers palliative care services in Soweto and all surrounding areas.

The ICPCN staff regularly submits abstracts to present at palliative and non-palliative conferences to raise awareness of the need for palliative care for children and the response is often positive. At the AIDS Conference 2016 that took place in Durban, ICPCN was the only palliative care organisation present.

India
Following the Indian Association of Palliative Care Conference (IAPCON) in Coimbatore, a team from the International Children’s Palliative Care Network (ICPCN), the Indian Association of Palliative Care (IAPC), the Worldwide Hospice and Palliative Care Alliance (WHPCA), and the Indian Association of Paediatrics (IAP), took the opportunity to advocate for palliative care with key personnel within the Ministry of Health, the World Health Organization, the Indian Council of Medical Research and the Medical Council of India in Delhi. They stressed the importance of palliative care for both adults and children and its place within Universal Health Coverage, along with the WHA resolution in 2014, and the need for the integration of palliative care into existing structures, and the commitment of India, as a member state, to implement this resolution.

Indonesia
Prof Julia Downing visited Rachel House in Jakarta, an NGO pioneering children’s palliative care in Indonesia, to explore ways of collaboration, but also to advocate for children’s palliative care with different organisations, including both clinical and academic. Rachel House, with 10 years of experience in palliative care, is keen to start building a body of evidence supporting the call to further develop the needed palliative care system in Indonesia. Together with Prof. Downing, Rachel House organized and hosted Indonesia’s very first round-table discussion about the possibility of carrying out evidence-based research supporting the need for palliative care in Indonesia. At the round-table discussion, representatives from the Faculties of Nursing from Universitas Indonesia, Universitas Padjadjaran, Universitas Muhammadiyah Yogyakarta and Universitas Esa Unggul, together with Rachel House and Prof. Downing explored the next steps along the journey into research. Rachel House and Prof. Downing also met with leaders from Jakarta’s Cipto Mangunkusumo National Referral Hospital and Dharmais National Cancer Hospital to explore the options.

Eastern Europe
Together with Bundesverband Kinderhospiz e.V. ICPCN, through their Board Chair, Sabine Kraft, organised a two day meeting for advocates for children’s palliative care within Eastern Europe in Berlin. The meeting was to discuss a strategy for strengthening children’s palliative care in the region, to network and to visit a children’s palliative care programme in Germany. The team included advocates from Russia, Belarus, Ukraine, Romania, Latvia, and Kyrgyzstan. Following an informative visit to a local children’s hospice – participants discussed developments in their countries and how we can support each other in the ongoing development of children’s palliative care within Eastern Europe.

Latin America
The occasion of the ICPCN conference in Argentina provided a great opportunity for
advocating for children’s palliative care not only in Argentina, but also in the surrounding countries. Key individuals from the Ministry of Health, the Argentine Society of Paediatrics, the Argentine Palliative Care Association, plus other stakeholders attended the conference on various occasions including the opening ceremony, and the recognition of some of the leading children’s palliative care advocates within the region. The conference also gave the opportunity for many individuals locally to attend the conference and to learn more about what is happening in children’s palliative care around the world.

**Advocacy for palliative care within related organisations**

ICPCN is working with a variety of stakeholders to develop and promote children’s palliative care within their organisations. These include Child Cancer International, a parents group, World Child Cancer, the Rare Diseases Association, AORTIC, the International AIDS Society (IAS) and the Regional Inter-Agency Task Team for children with HIV in Eastern and Southern Africa (RIATT-ESA) and ICPCN chairs the Care and Support working group for RIATT.

**Regional Advocacy**

ICPCN works closely with regional palliative care organisations to advocate for children’s palliative care regionally. For example:

- **Africa** - ICPCN and APCA co-chair the recently formed African Children’s Palliative Care Network, and support each others as opportunities in the region arise.
- **Europe** - ICPCN is also a member of the steering group of the EAPC Children’s Task Force who are committed to strengthening the voice of children’s palliative care within the European region. Following on from the meeting in Berlin there is also an informal Eastern European network who are linked to the ICPCN.
- **Asia** - The APHN have an International Paediatric Palliative Care Discussion Forum – Co-ordinated by the Asia Pacific Hospice Network, it is supported by ICPCN and it gathers practitioners from different disciplines who work in the field of children’s palliative care to provide networking and mutual support.
- **Latin America** – The Latin American Palliative Care Association (ALCP) was involved in the ICPCN children’s conference in Argentina, which was a good opportunity to strengthen and develop links within the region.
2nd International ICPCN Conference - Buenos Aires, 18 - 21 May 2016
2nd ICPCN Conference

Despite many challenges, including presenting a conference in two languages (English and Spanish) the 2nd ICPCN Conference “Palliative Care for Children - NOW” held in Buenos Aires, Argentina from 18 - 21 May 2017 was a great success and well-supported by health professionals from the Latin American region.

The financial support we received enabled us to show a profit, and the success was mainly due to the Conference co-chairperson and ICPCN Trustee, Dr Rut Kiman, who, working together with a small team from the region and supported by the ICPCN staff, accessed many sponsorships to cover the basic costs of the conference including a donation of the venue from the Argentine Paediatricians Society; refreshments during the conference; the venue and refreshments for the social event; conference bags; programmes and many other smaller items. Financial support was also received from the Argentine Ministry of Health and UNICEF Argentina.

The International Association of Hospice and Palliative Care (IAHPC) provided 5 travel bursaries and that organisation’s president, Liliana de Lima, attended the conference together with the President of the Latin-American Palliative Care Association, Dr Tania Pastrana. Written messages of support for the conference were received from Pope Francis and the Duchess of Cambridge; and video messages were sent by Archbishop Desmond Tutu; Dr Marie-Charlotte Bousseau from WHO; the Bishop of Swaziland (who hails from Argentina) and from some of our ICPCN Ambassadors and Champions.

There were 150 people at the 6 pre-conference workshops and a total of 410 people from 40 countries who registered for the full 3 day conference. Achievement awards were given to four leaders in the field of children’s palliative care in Argentina and Latin America. The programme was comprehensive and varied with excellent speakers. The Big Debate on euthanasia received a great deal of comment and attention and was very respectfully debated by Dr Eduard Verhagen (Netherlands) and Dr Richard Hain (UK). With 13 Latin American countries represented and the majority of attendees from the region we believe that our decision to hold a conference in this region was justified.

At the end of the Conference the “Commitment of Buenos Aires” was launched, which calls on well-resourced programmes and countries to share their resources with those in need. With 98% of children needing palliative care in low and middle income countries where resources are limited, this could be an effective way of supporting development to those most in need.

A more detailed description of the conference and many of the presentations can be found on the ICPCN website.
Commitment of Buenos Aires

We believe that all children with life-threatening and life-limiting conditions have the right to receive quality palliative care provided by trained professionals and support workers, wherever they live in the world.

We are concerned about the large and unmet needs of children requiring palliative care, especially in low and middle-income countries where the need is greatest.

We call on all governments to implement the World Health Assembly Resolution 67.19 of May 2014 on Palliative Care to ensure equitable access to palliative care, which includes pain and symptom relief, psycho-social, emotional and spiritual support for neonates, infants, children and young people, and their families.

As palliative care practitioners and advocates we recognise that disparities exist within and between countries and services, but collectively we are a rich resource of knowledge and skills. We therefore commit to share all that we can, and to collaborate with the World Health Organization (WHO), UNICEF, governments and other relevant groups to achieve our global vision of palliative care for all children who need it.

21st May 2016
Buenos Aires, Argentina
Education

Education is a core component of ICPCN’s work to ensure that all those who need education on children’s palliative care can access it. One of the ways that ICPCN does this is through its elearning programme alongside face-to-face programmes where possible. Examples of some of ICPCN’s education activities include:

Ukraine
Supporting work in Ukraine. ICPCN has been working closely with the team in Ukraine, and it is exciting to hear of the work that is going on in the country on CPC. As well as meeting key government stakeholders alongside the International Renaissance Foundation, ICPCN was involved in training with the Tabletochki Foundation alongside Dr Natasha Savva from the Russian Children’s Hospice Foundation.

Malaysia
In Kuala Lumpur ICPCN was helping facilitate training at Hospis Malaysia alongside Dr Ross Drake from Starship Children’s Hospital’s palliative care unit in Auckland and Dr Leeai Chong from Hospis Malaysia. The training focused on different aspects of children’s palliative care, culminating in some case discussions and a focus on research.

Lesotho
In January 2017, with funds from OSISA, ICPCN trained 26 health care workers in CPC from all the regions of Lesotho with the aim of spreading the availability of services throughout the country. The basic training will be followed by training of trainers to ensure growth and an increase in the number of trained health workers in the country. Clinical placements will also be arranged for participants in nearby Bloemfontain.

Swaziland
After training health professionals in 2015, it was necessary to develop documents that would support them in providing the service to children and their families. In consultation with relevant stakeholders, the following documents were produced:

• National Guidelines to guide the practice of the health workers
• Curriculum for training health workers in palliative care for children
• Two manuals for training in children’s palliative care, one for participants and one for facilitators.

These were to be distributed to all the regions in the country.

The Netherlands
The national CPC association – Stitching Pal – are using some of the elearning modules to train their staff, particularly new volunteers who do not know much about CPC.

E-Learning
ICPCN has a bespoke Moodle Platform from which it runs its e-learning programmes. E-learning programmes are available for participants to join in at any time and are mostly linked to individual learning, with clear application of what has been learnt. To date over 1,700 participants from approximately 120 countries have undertaken the e-learning
programmes. Whilst not all of them have completed the assignments or carried out the assignments, a large number have completed it all and found the courses to be very helpful. Courses exist in a number of languages including: English, French, Russian, Serbian, Hindi, Mandarin, Dutch, and Hindi and are being translated into other languages, such as Arabic and Czech. To date the largest number of participants has come from Europe, followed by North America, Asia, Africa and Latin America. Courses are currently free and cover a range of topics including, but not limited to, Pain Assessment and Management, End of Life Care and Perinatal Palliative Care. Further courses are under development and will in time be uploaded to the website (http://www.elearnicpcn.org).

Other education and training opportunities included:
- In July, Joan Marston was the international speaker at the international Pediatric Pain and Palliative Care Master Class in Minneapolis.
- In August ICPCN presented a CPC workshop at the APCA and WHPCA Conference in Kampala, Uganda, and then a 2 day Master Class at Mildmay in Kampala.
- ICPCN representatives presented at a Seminar in Cape Town.
- ICPCN, through Prof Julia Downing, is the External Examiner for the Diploma in Children’s Palliative Care run by Mildmay, and she is also involved in marking both Masters and PhD thesis in this area.

**Evaluation of the impact of the ICPCN training face-to-face and e-learning**

One of the challenges to the provision of CPC is a lack of education and knowledge in the field. Thus ICPCN developed an education programme including both online and face-to-face programmes. Whilst ICPCN has expanded both of these programmes, no evaluation had been undertaken as to the impact of the programmes.

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 including those in Kenya, Sudan and Zambia, and e-learning courses, were invited, via email, to take part. A further survey is due to be administered in the course of 2017.

100 participants completed the survey, 48% from sub-Saharan Africa, 26% from Europe, 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.

ICPCN’s education programme is having an impact on the provision of CPC, and a variety of training methods can be employed. Nurses have benefited from these trainings programmes and have been empowered to provide CPC. Whilst not as effective as face-to-face training,
Research

Generating and utilising the evidence base on children’s palliative care is vital for the work that ICPCN undertakes. Sometimes ICPCN takes part in a research project e.g. on standards for implementation of the WHA Resolution in Africa and on other occasions ICPCN is responsible for implementing research or signposting members to important studies. Following the results of the Delphi study to prioritise global CPC research (footnote reference), ICPCN has been involved in the following studies amongst others:

• Identifying the need for children’s palliative care – this study was published in January 2017 in the Journal of Pain and Symptom Management and identified that 21.6 million children globally need access to palliative care with over 8 million requiring specialist palliative care provision.
• Children’s understanding of illness, death and dying – ICPCN is working with Sarah Friebert and Paula McPoland on this study which is being implemented initially in the USA, Haiti and South Africa – data collection is still ongoing but it is hoped that it may be expanded to other countries at a later date.
• Development of the children’s POS – ICPCN were involved in the initial development of the children’s outcome scale which is currently being validated further by Eve Namissango from the African Palliative Care Association at Kings College London, and ICPCN are involved in supervising the study.
• Various studies looking at the use of the 2-step analgesic ladder, e.g. one which was undertaken in Uganda in conjunction with Penn State University

Dissemination

This is an important part of the role of ICPCN and alongside disseminating materials on their website, ICPCN is frequently involved in presenting papers at conferences. Some of the conferences and seminars where ICPCN have been involved include:

• APCA/WHPCA Conference in Uganda in August 2016.
• UICC World Cancer Congress: Mobilising Action: Inspiring change, in Paris in November
• Hospice 23 Conference
• International Pediatric Pain and Palliative Care Master Class
• Seminar in Cape Town organised by the national CPC network, PatchSA
• 1st Austrian PPC Conference in Salzburg
• Palliative care: a global priority. Perspectives on integration and health systems strengthening held in Edinburgh
• Spirituality in Healthcare Conference in Pretoria
• 3rd Paediatric Palliative Care Conference: A Global Gathering held in Rome
• Global Seminar on ‘Rethinking care toward the End-of-Life’ held in Salzburg
• Indian Association of Palliative Care Conference in Coimbatore
• RCN education forum

ICPCN is also partnering on the development of the Cardiff Paediatric Palliative Care Conference to be held in July 2017 and this should build on the success of previous years. Work has also begun on the development of the next ICPCN conference in Durban in May/June 2018.
Publications
ICPCN has worked hard with regards to publications in the past year. Publications have included, but are not limited to:

Financial Review

An extract from the Audited Consolidated Financial Statements for the year ended 28th February 2017 is as follows:

Overall income for the year amounted to £306,354. This was made up primarily of grants from True Colours Trust, Monument Trust, the Open Society Foundations and the Open Society Initiative for Southern Africa.

The Charity’s expenditure for the past financial year amounted to £302,945 and was spent on various projects delivered during the year.

Raising funds remains a constant challenge and we are continuously exploring numerous avenues for new potential funders. We achieved some success during this year, and would like to thank the following:

- Heb Ffin
- Krebsallianz
- OSI SA
- OSI
- True Colours Trust
- The United States Cancer Pain Relief Committee

A breakdown of income and expenses for the financial year March 2016 to February 2017 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>£91,898</td>
</tr>
<tr>
<td>Open Society Foundation</td>
<td>£99,060</td>
</tr>
<tr>
<td>Open Society Initiative for Southern Africa</td>
<td>£51,655</td>
</tr>
<tr>
<td>Krebsallianz</td>
<td>£629</td>
</tr>
<tr>
<td>Global Giving</td>
<td>£1,822</td>
</tr>
<tr>
<td>General Fund - unrestricted</td>
<td>£61,470</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>£306,534</td>
</tr>
</tbody>
</table>

![ICPCN Income Resources 2017](image-url)
### Expenditure: Direct costs

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governance costs</td>
<td>£4,746</td>
</tr>
<tr>
<td>UK Travel</td>
<td>£1,331</td>
</tr>
<tr>
<td>Travel in Africa</td>
<td>£11,542</td>
</tr>
<tr>
<td>International travel</td>
<td>£16,068</td>
</tr>
<tr>
<td>Project Costs</td>
<td>£31,298</td>
</tr>
<tr>
<td>Educational Grants</td>
<td>£728</td>
</tr>
<tr>
<td>Fundraising costs</td>
<td>£608</td>
</tr>
<tr>
<td>Conference Costs</td>
<td>£32,401</td>
</tr>
<tr>
<td>Salaries &amp; Wages</td>
<td>£52,330</td>
</tr>
<tr>
<td>Consultancy Costs</td>
<td>£23,976</td>
</tr>
<tr>
<td>Consultancy Expenses</td>
<td>£6,416</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£181,444</strong></td>
</tr>
</tbody>
</table>

### Expenditure: Support Costs

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admin &amp; Managment Fees</td>
<td>£4,123</td>
</tr>
<tr>
<td>Postage, Printing &amp; Stationery</td>
<td>£1,406</td>
</tr>
<tr>
<td>IT Expenses</td>
<td>£976</td>
</tr>
<tr>
<td>Telephone Costs</td>
<td>£6,001</td>
</tr>
<tr>
<td>Consultancy Costs</td>
<td>£318</td>
</tr>
<tr>
<td>Bank Charges</td>
<td>£763</td>
</tr>
<tr>
<td>Website Development Costs</td>
<td>£270</td>
</tr>
<tr>
<td>Training Costs</td>
<td>£398</td>
</tr>
<tr>
<td>Accounting Fees</td>
<td>£52</td>
</tr>
<tr>
<td>Insurance</td>
<td>£1,147</td>
</tr>
<tr>
<td>Staff Expenses</td>
<td>£2,968</td>
</tr>
<tr>
<td>Marketing, Advertising, Promotions</td>
<td>£1,190</td>
</tr>
<tr>
<td>Foreign Exchange Adjustments</td>
<td>-£3,147</td>
</tr>
<tr>
<td>Salaries &amp; Wages</td>
<td>£104,143</td>
</tr>
<tr>
<td>Depreciation</td>
<td>£893</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£121,501</strong></td>
</tr>
</tbody>
</table>

### Summary

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff costs</td>
<td>£156,473</td>
</tr>
<tr>
<td>Travel costs</td>
<td>£28,941</td>
</tr>
<tr>
<td>Direct project costs</td>
<td>£65,035</td>
</tr>
<tr>
<td>Office &amp; admin costs</td>
<td>£17,040</td>
</tr>
<tr>
<td>Consultancy Costs</td>
<td>£30,710</td>
</tr>
<tr>
<td>Governance Costs</td>
<td>£4,746</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£302,945</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:

Prof Maryann Muckaden (Chair)  India
Ms Sabine Kraft (Vice Chair)  Germany
Mr Richard Carling (Treasurer)  United Kingdom
Dr Zipporah Ali  Kenya
Ms Sharon Baxter  Canada
Dr Delia Birtar  Romania
Dr/Prof Hanneke Brits  South Africa
Ms Lynna Chandra  Indonesia
Dr Stephen Connor  USA
Mr Peter Ellis  United Kingdom
Dr Anna Garchakova  Belarus
Mrs Lynda Gould  China
Ms Dianne Grey  USA
Dr Rut Kiman  Argentina
Mrs Fatia Kiyange  Uganda
Dr Marianne Phillips  Australia
Mr Paul Quilliam  Australia
Dr Marli Roberson  Canada
Joan Marston  Chief Executive (ex officio member)
Prof Julia Downing  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
• Krebsallianz
• Heb Ffin
• The United States Cancer Pain Relief Committee
The ICPCN is administered from within South Africa.
Postal Address:
Cluster Box 3050
Assagay
3624
South Africa

Telephone: +27 (0)82 897 4420
Email: info@icpcn.org
Web: www.icpcn.org

ICPCN is a registered charity in England & Wales (No: 1143712)
ICPCN Operations is registered in South Africa as a Section 21 (Non Profit) Company (2011/001648/08)
and a Public Benefit Organisation (PBO 930043272)