Message from our Chief Executive

As I look back on the 2018/2019 ICPCN year, it has been a year of excitement, developments, collaboration, hard work, celebration and challenges. The 3rd ICPCN conference was held in Durban in May/June 2018. The team worked hard to achieve what was an amazing event, with participants attending from around the world getting a taste of the multi-cultural nature of South Africa and Durban in particular. The ICPCN team worked hard alongside the team from Umduduzi, PATCH-SA and HPCA, collaborating together to achieve a wide variety of pre-conference workshops, plenary and parallel sessions of a high standard, workshops, meet-the expert sessions, poster presentations and the social calendar. The dinner on the Friday evening was a celebration of all that has been achieved, and a great opportunity to ‘let our hair down’ and dance!

Whilst the conference was a big focus of the year, this went alongside the ongoing activities of ICPCN in advocating for and supporting the development of children’s palliative care. Our advocacy activities continue at a pace, both at the international, regional and national levels alongside our members. We are grateful for the leadership of Busi Nkosi, who has been instrumental in much of our advocacy work, particularly within the African region. ICPCN continues to work towards official relations with the World Health Organization and, whilst we do this, we are grateful to the WHPCA, IAHPC and other organisations for working with us on global advocacy initiatives.

Communication is a theme that runs through all of our work at ICPCN. As well as heading up the local organising committee for the conference, Sue Boucher continued to develop our communication throughout the year. Communication plays an important role and it has been good to see the revamping of the ehospice platform, the expansion of the #Hatson4CPC campaign and the amount of media coverage that we were able to secure around the time of the conference in South Africa. Lorna Sithole was responsible for coordinating the various media interviews and keeping track of who needed to be where, when and speaking to whom. Media exposure and ongoing advocacy are important components of our conference, and we were delighted by the attention that children’s palliative care received, along with local organisations such as Umduduzi.

Our education programme, in particular the elearning programme, continues to develop from strength to strength. It was great that Alex Daniels, our Education Officer, was able to attend the Rome children’s palliative care conference and then go on to Moldova to help with some children’s palliative care training. We continue to explore ways in which we can improve and develop our e-learning programme. A review of the Moodle platform has been an important step in this process, with changes planned for the next year in order to improve the user’s experience and overcome a few challenges we have been experiencing with the site.
Administration and finance activities keep an organisation moving, yet are often done behind the scenes. We are grateful to Barbara Steel, our Admin and Finance Officer, for supporting all of us in our work, and ensuring the smooth working of the organisation.

Whilst it was great to hear of all of the global developments at the ICPCN conference and in Rome, and from our ICPCN members, we are also aware of the millions of children globally who do not have access to palliative care. This fact, highlighted at both the International and UK launches of the Lancet Commission report, keeps us focused on the work of ICPCN. This year has given us an opportunity to reflect on the work undertaken and all that has been achieved, as well as looking forward and thinking about our next steps—where do we go from here, and how? As we do this, we are also aware of the challenging economic and political environments in which we are all working, and need to think about what that means for all of us working in children’s palliative care.

Recognising this, ICPCN is committed to its vision that all children living with a life-limiting or life-threatening condition and their families, will have seamless access to palliative care in order to alleviate serious health-related suffering and enhance their quality of life. As ICPCN takes those next steps, we look forward to future collaborations which will facilitate increased access to children’s palliative care globally.

Prof. Julia Downing
Our year in review...

March 2018
• Prof Julia Downing invited to share her Leadership Journey at the Belfast Health and Social Care Trust, Celebrating Nursing and Midwifery, in Belfast, Northern Ireland.
• ICPCN worked in partnership with the Mozambique Palliative Care Association (MOPCA), the African Palliative Care Association (APCA) and True Colours Trust to support a CPC training course in Maputo.
• Prof Julia Downing Co-Chaired the UK APM Supportive and Palliative Care Conference held in Bournemouth, UK.

April 2018
• Launch of the Lancet Commission report in Miami, USA.
• ICPCN shared some of their work at the RCN Research Conference in Birmingham, UK.
• ICPCN participated in the Palliative Care Leadership Training in Uganda through the University of Edinburgh and the Makerere/Mulago Palliative Care Unit.
• Remote meeting of the African Children’s Palliative Care Network (ACPCN) Steering Committee held.

May 2018
• ICPCN presented on children’s palliative care at the Festival Della Scienza Medica in Bologna.
• ICPCN participated in the Founding Assembly and First National Symposium of the China Association for Life Care (CALC) Children’s Palliative Care and Family health Care Professional Services Committee, held in Beijing, China. ICPCN were represented by Prof Julia Downing (Chief Executive) along with Lynda Gould MBE from Butterfly House China (ICPCN Board member) and Paul Quilliam from Hummingbird House in Australia (ICPCN Board member).
• ICPCN Board of Trustees Annual Meeting held prior to the ICPCN conference in Durban.
• ICPCN Strategic Planning Meeting held in Durban.
• The 3rd ICPCN conference “Inspiration, Innovation, Integration” was held in Durban, South Africa, and was attended by 250 participants from 41 countries.

June 2018
• ICPCN presented on children’s palliative care internationally at a meeting in Heidelberg Germany organised by the ICPCN Chair, Sabine Kraft.

August 2018
• ICPCN attended the 10th Anniversary Conference of the Makerere/Mulago Palliative Care Unit in Kampala, Uganda.
• ICPCN participated in the inaugural meeting of the WHO Global Initiative for Childhood Cancer in Geneva, Switzerland.
• Remote meeting of the African Children’s Palliative Care Network (ACPCN) held.
• ICPCN attended the SCCA conference in Lesotho to continue advocacy for children’s palliative care.

September 2018
• ICPCN involved in the face-to-face meeting of the MSc in Palliative Care held at Cardiff University.
• Meetings held with Prof Alan Stein and his team at Oxford University with regards to
adapting the guidelines for communicating with children about their or their parent’s illness, for low- and middle-income settings.

- ICPCN discussed the benefits of palliative care for children with cancer at a Palliative Care and Cancer Symposium at Hospis Malaysia in Kuala Lumpur.
- ICPCN gave a presentation on Children’s Palliative Care to nursing students at the University of Johannesburg, South Africa.
- ICPCN was represented at the Rare Diseases conference in South Africa.

**October 2018**

- ICPCN co-ordinated a workshop on children’s palliative care at the World Cancer Congress: Strengthen, Inspire, Deliver held in Kuala Lumpur. Also participated in a session on Palliative Care Outcome Measurement.
- ICPCN’s Chief Executive was interviewed by ecancer.
- ICPCN participated in a paediatric palliative care symposium: Advancing Paediatric palliative Care in Indonesia hosted by Rachel House in Jakarta, along with participating in other advocacy activities whilst in Jakarta.
- ICPCN ran a successful #HatsOn4CPC campaign with events held in 32 countries.
- ICPCN participated in World Hospice and Palliative Care Day with the theme: “Palliative Care – Because I Matter”.
- The Children’s Palliative Care Foundation Inauguration and Children’s Palliative Care Symposium 2018 was held in Hong Kong. ICPCN are part of the advisory group for the children’s Palliative Care Foundation and presented at the Inauguration.
- ICPCN taught on the Masters in Children’s Palliative Care run by The Accademia Delle Scienze di medicina Palliativa (ASMEPA) in Bologna, Italy.
- ICPCN submitted input to the Global Conference on Primary Health care in Astana, Kazakhstan.
- ICPCN supported the 4th Global Gathering on Paediatric Palliative Care held by the Maruzza Foundation in Rome, Italy.
- ICPCN facilitated training on Children’s Palliative Care in Chisinau, Moldova. The training was made possible by partnerships between Coram Deo, Krebsallianz, the School of Public Health, and Hospices of Hope Moldova, Cancer Institute and ICPCN.

**November 2018**

- The Kenyan 5th National Palliative Care Conference: Investing in Palliative Care for Universal Health Coverage, was held in Nairobi. ICPCN co-facilitated a workshop on children’s palliative care, as well as giving a plenary presentation on paediatric palliative care.
- ICPCN participated in the international conference in palliative care held in Minsk, Belarus, organised by past ICPCN Board member Anna Garchakova, sharing the ICPCN experience.
- ICPCN took part in the Palliative Care Leadership Training in Uganda through the University of Edinburgh and the Makerere/Mulago Palliative Care Unit.
- ICPCN supported a Global Palliative Care Day on Healing the Nations: Leaving None Behind held with the University of Edinburgh and Cairdeas International Palliative Care Trust in Scotland.
- ICPCN was represented at a meeting of the Children’s Rights Network in Southern Africa (CRNSA) in Pretoria, South Africa.
- ICPCN participated in the RIATT-ESA Learning and Linking Forum in Sandton, Johannesburg.

**December 2018**

- ICPCN gave a keynote address at the First International Oncology and Palliative Care Nursing Conference held in Bethlehem, organised by Bethlehem University and Medical Aid for Palestinians.
• ICPCN continued to support the development of children’s palliative care in Bologna, Italy through the Fondazione Hospice MariaTeresa Chiantore Seragnoli.
• Lorna Sithole moved on from her role as Media and Marketing Officer at ICPCN.

January 2019
• ICAn inaugural meeting was held in the UK on Paediatric Palliative Care Education and Training: Where we are now and how to get where we want to be? ICPCN were invited to participate and to share about their education programmes, both on-line and face-to-face.
• The Kick-Off meeting was held for the Horizon2020 project ‘MyPal: Fostering Palliative Care of Adults and Children with Cancer through Advanced Patient Reported Outcome Systems’. ICPCN are part of this three-year project.

February 2019
• ICPCN participated in the 26th Annual Conference of the Indian Association of Palliative Care in Kochi, India, co-ordinating a children’s palliative care workshop, and presenting on their impact of their work.
• The 1st World Children’s Hospice Forum - Children’s Palliative Care: Receiving the torch from the World’ was held in Tokyo, Japan, organised by the Yokohoma Children’s Hospice Project. Alongside colleagues from the UK and the Netherlands, ICPCN presented on the global status of children’s palliative care.
• ICPCN presented at the Médecins Sans Frontières (MSF) and the Belgian Pain Societies thematic symposium on “Pain in victims of torture, conflict and refugees” in Brussels.

ICPCN Staff

From left to right: Lorna Sithole (Media & Marketing Officer); Alex Daniels (Education Officer); Barbara Steel (Admin and Finance Manager); Sue Boucher (Director of Communications); Busi Nkosi (Director of Advocacy); Prof Julia Downing (Chief Executive);
3rd ICPCN Conference in pictures...
Communication & networking

As the only global children’s palliative care membership organisation, ICPCN connects people who care about and care for children with life threatening and life limiting illnesses from all corners of the world. This includes medical professionals, therapists, parents of children with life threatening and life limiting illnesses and children with palliative care needs.

ICPCN is a repository for information on children’s palliative care and provides a global platform for networking, advocacy, education, research and technical support. The website provides the central hub of the ICPCN’s communication service, with links to the International Children’s edition of ehospice, edited by ICPCN, our social media pages (Facebook, Twitter and Instagram), regular blogs, notices and regular electronic news bulletins.

The organisation is regularly asked to and succeeds in connecting professionals across the world for the purpose of research, training, mentoring, interning and experiential learning opportunities.

Membership
ICPCN membership spans 126 countries and all regions of the world and this was recently reviewed in order to be compliant with the new data protection requirements (GDPR). Contact details of organisations belonging to ICPCN can be found on the website. In addition, a regularly updated and interactive map of services that provide and promote palliative care for children can be accessed on the site. This allows ICPCN to stay informed of the development of services worldwide and also serves to highlight where the greatest gaps in provision may exist.
The ICPCN Website
The ICPCN website is kept relevant with regular updates related to news, events, scholarships and useful research and education resources. The events calendar provides timely information on international conferences, workshops, study days and training opportunities. Information on certificate courses, diplomas, and post-graduate qualifications in children’s palliative care can also be accessed via the website, along with links to the ICPCN e-learning website. The resources section links to numerous useful resources for practitioners. In the past 12-month period, more than 34,000 visits have been made to the ICPCN website, an increase of 2,000 users from the last reported period.

ehospice
Ehospice is a globally run news and information resource committed to bringing the latest news, commentary and analysis from the world of hospice, palliative and end of life care to readers. ICPCN is responsible for the content of the International Children’s edition. Over the past year, ehospice was migrated to a new WordPress website which meant a period of transition and adjustment. The loss of email alerts has impacted on the readership numbers. However, the International Children’s edition of ehospice has still managed to attract over 7,500 views per month. Published articles on this edition cover a wide spectrum of topics relevant to people who care for and care about children with life-threatening and life-limiting illnesses.

News Bulletins
Regular ebulletins are sent via email to our membership and to a growing number of people who have signed up to receive the bulletins via the website. These provide an overview of news from within the organisation and always feature a personal message from our Chief Executive. The ebulletin provides short summaries of articles of interest, with links to our website or ehospice page, where these articles can be read in full.

Social Media
Our social media sites provide an immediate and relevant space to share news on children’s palliative care, as well as highlighting global awareness days pertinent to children’s palliative care. ICPCN experienced a steady growth, when compared to the last reported period, across our social media platforms, and our social media following in this year was as follows:

- Facebook – 11,478 followers, an increase of 802
- Twitter – 2,743 followers, an increase of 560
- Instagram – 317 followers, an increase of 92

ICPCN curates content and uses social media to reach a broader audience than just those working in children’s palliative care, as well as to share important news, resources and research.

Broadcast media coverage
With the 3rd ICPCN Conference in Durban and the HatsOn4CPC campaign in 2018, ICPCN made use of a professional media company to assist with the marketing of these events within South Africa. This resulted in vastly increased exposure to the work of the organisation in mainstream media. This included coverage in local newspapers and a number of nationally broadcast radio and live TV interviews, including one with Prof Julia Downing, our Chief Executive, and Dr Rajagopal, a plenary speaker, on SABC News during the conference.
Hats on for children’s palliative care
‘Hats on 4 CPC’ is a campaign initiated and co-ordinated by ICPCN. On the second Friday of October, people from all walks of life are asked to wear a hat to work or school to raise awareness and funds for children’s palliative care. Social media followers are asked to take a photo of themselves in a hat and post using the hashtag #Hatson4CPC. Companies, organisations and schools are encouraged to take 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. The design work for the campaign was created within the ICPCN communications department.

In its 5th year, the 2018 HatsOn4CPC campaign saw 23 events registered in 14 countries across the globe. However, we know that more events took place with evidence from social media of events being held in 32 countries (up from 27 in 2017) with a reach of 801 235 on Twitter and Instagram and 17 100 on Facebook.

3rd ICPCN Conference
Communication played a key role in the success of the 3rd ICPCN Conference held in Durban, South Africa in May and June of 2018. This included the development of the conference website to provide information, receive abstracts and process registrations. Promotional materials were developed and distributed along with information to encourage donations towards the running costs of the conference. All design work for the conference was created within the ICPCN communications department.
ICPCN Annual Report 2019

Advocacy

ICPCN continues to be involved in advocacy activities globally for children’s palliative care and collaborates with partners and stakeholders regionally and nationally as appropriate. 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 are as follows:

Global advocacy
ICPCN has a key role in advocating for children’s palliative care globally. ICPCN is part of the advocacy group for the Worldwide Hospice and Palliative Care Alliance (WHPCA) and works closely with WHPCA and the International Association of Hospice and Palliative Care (IAHPC) on global advocacy. ICPCN is therefore involved in co-ordinated advocacy campaigns to strengthen palliative care globally. These activities include our annual “HatsOn4CPC” campaign and the annual World Hospice and Palliative Care Day, with the theme for 2018 being that of ‘Palliative Care – Because I Matter’ with key input from palliative care stakeholders, including our Global Youth Ambassador Lucy Watts. ICPCN works on position statements and advocacy materials for specific events, such as the World Health Assembly, UN high level meetings, etc. Two key position papers developed this year with WHPCA and IAHPC were on Universal Health Coverage and Primary Health Care and Palliative Care.

Input into Global meetings included the Global Conference on Primary Health Care in Astana, Kazakhstan in October, inputting into presentations from the WHO and Lucy Watts. We also contributed to the Astana Declaration to ensure the inclusion of palliative care. The declaration has now been published and a palliative care team represented IAHPC, WHPCA and ICPCN at the meeting. ICPCN continues to work with other stakeholders to strengthen the palliative care input into various Global Plans, trying to strengthen the civil society voice on global health alongside the multilaterals.

ICPCN continues to work with the WHO in the process towards gaining official relations with the WHO which we hope will happen in the next few months. Meanwhile ICPCN works with IAHPC and WHPCA, who represent palliative care at the WHO Executive Board and WHA Assembly, with the inclusion of direct stakeholders in their delegations.

The Global Initiative for Childhood Cancer was launched in August at the WHO in Geneva. ICPCN has contributed to several of the working groups developing a Global Strategy for Childhood Cancer up to 2030. In response to the Lancet Commission Report, an ‘AfterLife’ committee was set up to try and ensure that the report has impact and recommendations are acted upon and ICPCN is an integral part of this.

Maintaining CPC awareness
Conferences offer captive audiences and are always targeted as a platform to raise awareness for CPC. Abstracts have been submitted and presentations made at various conferences, palliative and non-palliative care, throughout the year. Various universities have also been visited to make them aware of the need to integrate CPC in their curricula as stated by the WHA Resolution on palliative care. Position papers on CPC with childhood cancer and Primary Health Care have been made and posted on our website.
Strategic partnerships
Strategic partnerships have been formed with like-minded organisations to advance the course of CPC. Examples of these are Childhood Cancer International (CCI), where we are working with them on the WHO Childhood Cancer Initiative, along with CCI Africa, where we are working with them to appraise childhood cancer organisations for the provision of CPC in Africa.

South Africa
In South Africa there is collaboration with the Childhood Cancer Network of South Africa that comprises of organisations of parents of children with cancer and professionals working with children living with cancer. Our relationship with Rare Diseases South Africa and the Genetic Alliance of South Africa continues to be nurtured, as some children with rare diseases and genetic disorders need palliative care, and awareness for this need should be constantly raised in this population. Our long-term partnership with RIATT-ESA ensures that palliative care forms part of treatment and care for children with HIV and AIDS. The Child Rights Network of Southern Africa is currently developing a Child’s Rights Protocol for the SADC region to ensure children’s rights are realised and do not just remain on paper. The ICPCN forms part of this process to ensure the right to palliative care is included. ICPCN staff also contribute to Palliative Treatment for Children (PATCH) South Africa which is the national children’s palliative care network.

Working with AORTIC
A special interest group on palliative care has been set up by the African Organisation for Research and Training in Cancer (AORTIC) and ICPCN’s Chief Executive is the children’s palliative care representative on this group. They are planning a workshop for the AORTIC Conference in Mozambique in November 2019.

Hong Kong
ICPCN worked with the Hong Kong College of Paediatric Nursing on their position statement on paediatric palliative care, and spoke at the Children’s Palliative Care Symposium 2018 and the Inauguration of the Children’s Palliative Care Foundation. This was a great celebration and an important moment in CPC development in Hong Kong. ICPCN is an Honorary Advisor for the Children’s Palliative Care Foundation and are supporting their ongoing development.

Working with Regional Palliative Care Organisations
ICPCN works closely with regional palliative care organisations to advocate for children’s palliative care regionally. For example:

The African Children’s Palliative Care Network (ACPCN) was formalised in 2017 to help strengthen and develop children’s palliative care services in Africa. ICPCN works closely with the African Palliative Care Association (APCA) to co-ordinate the network. On 1st June 2018, at the ICPCN conference held in Durban, South Africa, the ACPCN held a meeting to develop a strategic plan to give direction to its activities. The meeting drew 27 participants from 14 countries i.e. South Africa; Lesotho; Eswatini; India; Sudan; Kenya; Uganda; Mozambique; Mauritius, Malawi, Zambia, Nigeria, Zimbabwe, USA. A plan with the following 6 objectives was developed:
1. To advocate for the need for children’s palliative care in Africa.
2. To advocate for the inclusion of children’s palliative care in health and other government policies.
3. To advocate for capacity building for children’s palliative care at all levels in Africa.
4. To advocate for the strengthening of research in CPC in Africa in order to inform policy, education and practice.
5. To advocate for strategic partnerships that promote access to children’s palliative care in Africa.
6. To advocate for the dissemination of African CPC models that can be utilised across the region.

To measure progress of their advocacy initiatives in the different countries, members of the ACPCN have developed evaluation tools. The Steering Committee of the ACPCN holds quarterly meetings to plan, implement and review their activities in different countries. The manager of programmes at the African Palliative Care Association is the chair of this committee.

The European Association of Palliative Care Children’s Task Force was launched in 2016 and ICPCN are part of the Steering Committee. During this year the task force actively planned for a full paediatric day at the EAPC congress held in Berlin, Germany in May 2019. The task force reviewed abstracts, planned speakers for the day and encouraged children’s palliative care professionals to register for the conference. The taskforce also organised and took part in a children’s palliative care stream for the European Academy of Paediatric Societies Conference in Paris in November 2018.

The EAPC Atlas of Palliative Care is due to be launched in Berlin in May 2019. The Task Force contributed to the Atlas being led by the University of Navarra, including collaborating on the development of the indicator questions and identifying key contacts in children’s palliative care across Europe.

The Association of Children’s Palliative Care in Eastern Europe and Central Asia was launched with a steering group from Belarus, Latvia and the Ukraine and they are keen to work with ICPCN to help develop their network.

The Asia Pacific Hospice and Palliative Care Network were active in the running of the UICC World Cancer Congress in Kuala Lumpur in October 2018. ICPCN co-ordinated a workshop on children’s palliative care at the congress, as well as participating in a pre-conference workshop held at Hospis Malaysia on palliative care and cancer care.

Latin America ICPCN is planning to collaborate with the ALCP for their next conference in 2020 to support the CPC network within the region. ICPCN is also working with some Latin American countries with regards to promoting CPC through the ICPCN e-learning programmes and building on our previous work in Argentina and Brazil.
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 run by others, e.g. the Lancet Commission report, and on other occasions ICPCN is responsible for implementing research or signposting members to important studies. During this year, ICPCN has been involved in a variety of studies including, amongst others:

- Children’s understanding of illness, death and dying – working with Sarah Friebert and Paula McPoland on this study. Data collection was carried out in Uganda as part of the national level projects undertaken by participants on the Ugandan Palliative Care Leadership Programme, run by the Makerere/Mulago Palliative Care Unit and the University of Edinburgh. A research team of ten worked on the study, including five leadership fellows from across Uganda. Analysis has been undertaken and themes identified. Abstracts have been submitted to several conferences and work is underway to publish the results of the study. Results of the Ugandan study are being compared with those from the USA and Haiti. Data collection is ongoing in South Africa.

- Development of the Children’s Palliative Outcome Scale. Following involvement in the initial development of the African C-POS, ICPCN has been co-supervising Eve Namisango from APCA who is undertaking her PhD at King’s College London. A further grant has been secured by King’s College to develop a similar POS for Europe and ICPCN are involved in this process, and co-supervising Lucy Coombes who is working on this grant and undertaking her PhD.

- ICPCN is involved in a study with Edge Hill University looking at issues around transitions. This year ICPCN has been involved in a systematic review looking at the specification, acceptability and effectiveness of respite care and short breaks for young adults with complex healthcare needs.

- ICPCN is working with Prof Alan Stein from Oxford University and his team on a GCRF grant “Developing guidelines for the communication of life-threatening illness to children in low- and middle-income settings” – which is a follow on from the Lancet Commission report. Guidelines produced for communicating with children about their own or their parents’ illness were developed in the UK and published in the Lancet. The aim of this collaborative research is to look at these guidelines from the perspective of low- and middle-income settings and revise as appropriate.

- ICPCN has contributed to the development of the EAPC Atlas of palliative care and the revised Global Atlas of Palliative Care, due to be published later in the year.

- Various other smaller studies looking at the management of pain in children, the use of the ICPCN Pain App and the impact of education on CPC service provision.

Remember the Spring: A History of the early pioneers of children’s hospice and palliative care

The True Colours Trust gave ICPCN a grant to enable Joan Marston to research and write up information on the early pioneers of children’s hospice and palliative care.

“When you drink the waters, remember the spring.” Chinese proverb
This is the first phase of a larger study to investigate the origins of the children’s hospice and palliative care movement through the narratives of the early pioneers, and then document the field’s history. It aims to identify “early” pioneers, include their personal narratives, and highlight their influence on the global development of the field.

Through a literature review, questionnaires to identified pioneers and present leaders and some personal interviews, a short list of pioneers was drawn up and those individuals interviewed in more depth over a period of 10 months.

Influences commonly identified were Dr Elisabeth Kübler-Ross and Dr Cicely Saunders. Pioneers developed unique and individual programmes that influenced others and later there was a move to network. The study also looked at what influenced the pioneers, who initiated pioneering programmes and who the early adaptors were.

The early pioneers envisioned their programmes long before they were established; had different reasons for their work; and had a willingness to collaborate. The results of the study can be found on the ICPCN website at http://www.icpcn.org/a-global-history-of-childrens-palliative-care/

Focus groups for the development of guidelines for communicating with children about illness and death were held in South Africa and Uganda
Education

Education is key to the development of children’s palliative care across the globe and increasing opportunities for health workers to improve skills, knowledge and shift attitudes is imperative. Training programmes, developed by ICPCN and presented in face to face and e-learning format, have an important role to play in this regard.

Examples of some of ICPCN’s education activities include:

Face to face training:

**Moldova**
In October 2018, in partnership with Krebsallianz, Coram Deo, Hospice of Hope, Cancer Institute and the School of Public Health, two children’s palliative care training workshops were held in Chisinau, Moldova. Both training workshops were facilitated by Dr Pavel Burykin, ICPCN Board member and Paediatrician at the Belarussian Children’s Hospice, and Maria Dyakova, a trained nurse, doctor and physical therapist with many years of CPC experience in Moscow. Each training workshop ran over three days and a total of 45 professionals participated including doctors, nurses, social workers and a teacher.

Decision makers in the Moldovan health care system have demonstrated their commitment to the development of CPC in the country. Hospices of Hope agreed to play a pivotal role in supporting participants through follow up and mentorship, thus ensuring theoretical components of the training are transferred to clinical practice. In addition, there are plans in place to expand training to mobile teams.

**Mozambique**
In March 2018, in partnership with the Mozambique Palliative Care Association (MOPCA), the African Palliative Care Association (APCA) and True Colours Trust (TCT), the first ICPCN led paediatric palliative care training course took place in Maputo. Eleven nurses and eight paediatricians attended the training that was held in the Unidade da Dor (Pain Unit) and a range of topics including communication with children and families, pain assessment and management, ethics, child development and play, grief and bereavement were discussed.

**Italy**
Through its work with the Fondazione Hospice MariaTeresa Chiantore Seragnoli, ICPCN has started teaching on the Masters in Children’s Palliative Care run by The Accademia Delle Scienze di medicina Palliativa (ASMEPA) in Bologna, Italy. ICPCN are also advising on other training programmes, including the development of staff to facilitate the opening and implementation of a children’s palliative care programme.

The E-Learning Programme
ICPCN offers participants free access to e-learning programmes from a dedicated Moodle Platform, www.elearnicpcn.org. Seven children’s palliative care courses are available in a range of languages including English, Spanish, Russian, Serbian, Dutch, Mandarin and Czech. Vietnamese and Hindi courses will be made available soon. Course topics include pain assessment and management, grief and bereavement, perinatal care and more. The course on ‘Symptoms Other Than Pain’ will be activated soon and an ‘Introduction to Research’ is due to be released later in the year.
E-Learning data
To date over 3,500 participants from approximately 124 countries have undertaken the e-learning programmes. During this year, 786 participants from 84 countries undertook the e-learning programmes including participants from 19 new countries. The following graphs illustrate the professional profile breakdown of these participants along with where they are from.
Over the course of the year:

- Mandarin: Four courses were activated and three more courses are currently under review.
- Hindi: Two Hindi courses are being reviewed by subject expert.
- Portuguese: Seventh course has been translated, loaded and currently under review by subject expert.
- Russian: Fifth course loaded, currently under review by subject expert.
- French: Seventh course being translated.
- Japanese: Course material translated and adapted to produce printed text by Yokohama Children’s Hospice Project.
- Work has commenced on upgrading the Moodle site and enhancing the user experience.

Developing an e-learning support team:

The ICPCN conference created an opportunity for subject experts to gather together to discuss support for the e-learning programme. A small group of volunteers have committed to support the platform by assisting with translations and grading assignments. Developing an e-learning support team is key to the promotion and development of courses across languages. The “Introduction to children’s palliative care” course is currently being translated into the following languages: Malay, Farsi, Italian, Hungarian and Hebrew.

Other educational support

Through its staff, ICPCN have continued to support the Diploma in Children’s Palliative Care run by Mildmay Uganda, as the external examiner for the course. The Chief Executive has also acted as the external examiner for several PhD’s and Masters’ Theses on children’s palliative care.

Pictures from the training undertaken in Moldova
During this year ICPCN undertook a review of our strategic plan 2015-2018 and developed a new one for 2019-2023.

Vision
- That all children living with a life-limiting or life-threatening condition and their families, will have seamless access to palliative care in order to alleviate serious health-related suffering and enhance their quality of life.

Mission
- ICPCN is the global umbrella organisation for children’s palliative care. Our mission is to achieve the best quality of life and care for children and young people with life-threatening or life-limiting conditions, their families and carers worldwide, by raising awareness of children’s palliative care among the public, health professionals and policy makers; advocating to governments and international organisations for the global development of children’s palliative care services; expanding the evidence-base for children’s palliative care; and sharing expertise, skills and knowledge with our global network of members.

Niche/ Unique Selling Point
- ICPCN is the only global organisation working to improve access to palliative care to the 21 million children worldwide who need it. ICPCN is recognised globally as the leader for CPC and has a globally renowned expert leadership, a wealth of educational resources and a network of members in over 125 countries. Through this network, ICPCN are uniquely placed to advise, educate and support at a national and regional level on best practice in CPC. As a central repository for information relating to CPC and with a global perspective of what is happening in the field ICPCN are in an ideal position to strategically advocate for the development and improvement of services, the creation of palliative care policies that include children and their families and the implementation of these policies, thus increasing access to CPC.
ICPCN’S STRATEGY 2019 - 2023

ICPCN’s goal for 2019 - 2023: To reinforce our position as the global expert in CPC, developing further as a hub of information, education and support services on CPC, and harnessing the network to deliver communications, advocacy, research, education and strategic development on behalf of ICPCN.

1. Communications
   To create a step-change in global awareness of ICPCN messages and access to ICPCN resources by reinforcing ICPCN’s position as the global authority on children’s palliative care and as a hub of information and resources, and by using a strategic combination of “pull” and “push” communications strategies to achieve a wider reach.

2. Advocacy
   To work towards inclusion of CPC in UHC worldwide by carrying out targeted strategic advocacy with world leaders at both a global, regional and national level, use of a suite of WHO-approved advocacy resources which are adaptable at country level, and by harnessing the network to use these resources to strategically advocate in their own localities.

3. Research
   To expand the evidence base for CPC through initiating research, collaborating on research in strategic areas, supporting other organisations with resources and signposting to carry out their own research and disseminating research for maximum impact.

4. Education
   To develop as a hub for the provision of training information; to provide high-quality CPC education which meets an identified global need; and to support and empower the ICPCN network to train in their own localities, thus improving the care given to children and their families.

5. Strategic Development
   To support the strategic development of children’s palliative care services worldwide through equipping and empowering the network with resources, training and mentorship; and facilitating the development of centres of excellence in strategic locations.

Funding
   To increase ICPCN’s revenue resilience, ensuring multiple revenue streams and sustainability.

Workforce and Governance
   To ensure ICPCN has staff with the right skills in the right place to deliver the strategic plan: along with the right board, governance and management procedures to effectively operate the organisation.

Collaboration
   To formalise collaborations with global organisations, regional networks, national associations, organisations, health professionals, and parents and children in the delivery of all ICPCN activities.
The ICPCN Conference and Dissemination

Following the successes of the 1st ICPCN conference in Mumbai and the 2nd in Buenos Aires the ICPCN team worked hard throughout the year to prepare for the 3rd ICPCN conference “Inspiration, Innovation, Integration”. The conference brought together 250 participants from 41 countries and was held in conjunction with local partners—Umduduzi Hospice Care for Children, Palliative Treatment for Children South Africa (Patch SA) and the Hospice and Palliative Care Association of South Africa (HPCA). It built on national and global developments in palliative care such as its inclusion in Universal health coverage (UHC), the Lancet Commission report on pain and palliative care and the sustainable development goals (SDGs), and aimed to raise the profile of children’s palliative care in KwaZulu-Natal (KZN) and nationally.

Seven pre-conference workshops were held prior to the conference on topics such as pain and symptom management, children’s palliative care within a humanitarian crisis, perinatal palliative care, research, developing programmes, ethical issues and difficult conversations in children’s palliative care. Delegates were welcomed in true Durban style at the welcome reception hosted by the City of Durban and uShaka Marine World.

The opening plenary included entertainment from the Open Air School and Hillcrest Primary School, and inspirational talks from the Member of the Executive Council (MEC) for Health,
a representative of the World Health Organization (WHO), the Chief Executive of ICPCN and the Noble Peace Prize Nominee Dr MR Rajagopal from Pallium India. Plenary sessions were interspersed throughout the conference with 56 oral concurrent presentations and workshops, six ‘Meet the expert sessions’ 100 poster presentations and the South African Premier of the film ‘Hippocratic: 18 Experiments in gently shaking the world’.

There was a great feeling of networking and learning throughout the conference, with the conference being well evaluated, and an increase in the level of presentations and research from previous conferences demonstrating the steps that are being taken in children’s palliative care globally.

**Dissemination**

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

- Belfast Health and Social Care Trust: Celebrating Nursing and Midwifery, - March 2018
- APM Supportive and Palliative Care Conference: Towards evidence based compassionate care, Bournemouth, UK - March 2018
- Festival Della Scienza Medica - Fourth Edition – Time to Care: Bologna – May 2018
- Building Momentum for Palliative Care: Transforming Lives, Changing Systems, Bringing Hope. Mulago Hospital, Kampala, Uganda. August 2018.
- Martin House Research Centre Conference: University of York, UK. September 2018
- Palliative Care and Cancer Symposium: Hospis Malaysia, Kuala Lumpur, Malaysia October 2018.
- Children’s Palliative Care Symposium 2018 cum Children’s Palliative Care Foundation Inauguration. Hong Kong, October 2018.
- International CPC Conference, Belarus: November 2018
- 5th National KEHPCA Palliative Care Conference, Nairobi, Kenya. November 2018
- Bethlehem University First International Oncology and Palliative Care Nursing Conference: Bethlehem, Palestine. December 2018.
- 26th International Conference of Indian Association of Palliative Care, Kerala, India. February 2019
- World Children’s Hospice Forum “Children’s hospice/Children’s palliative care: receiving the torch from the world, for the children in Japan” Yokohama, Japan. February 2019

**Publications**

ICPCN has contributed to numerous publications in the past year. Publications have included, but are not limited to:


• Sue Boucher wrote a collaborative article with Tracey Brand and Dr Julia Ambler on the importance of communication in children’s palliative care for Oncology Buddies magazine.
# Finance

An extract from the draft consolidated Financial Statements for the year ended 28 February 2019 is given below.

Overall income for the year amounted to £223,762. This was made up primarily of grants from the Open Society Foundation, True Colours Trust and the United States Cancer Pain Relief Committee.

The charity’s expenditure for the past financial year amounted to £226,121 and was spent on various projects delivered during the year.

Raising funds remains a constant challenge and we are continuously exploring numerous avenues for potential new funders.

Data for March 2018 to February 2019 still to be confirmed.

## Income

<table>
<thead>
<tr>
<th>Funder</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>True Colours Trust</td>
<td>£42,100</td>
</tr>
<tr>
<td>True Colours Trust: Education</td>
<td>£24,850</td>
</tr>
<tr>
<td>True Colours Trust: Strategic Plan Project</td>
<td>£6,000</td>
</tr>
<tr>
<td>Open Society Foundation</td>
<td>£54,300</td>
</tr>
<tr>
<td>United States Cancer Pain Relief Committee</td>
<td>£52,024</td>
</tr>
<tr>
<td>Krebsallanz</td>
<td>£4,055</td>
</tr>
<tr>
<td>GCRF Oxford University</td>
<td>£9,583</td>
</tr>
<tr>
<td>ICPCN Conference 2018</td>
<td>£19,175</td>
</tr>
<tr>
<td>General Fund - Unrestricted</td>
<td>£11,675</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£223,762</strong></td>
</tr>
</tbody>
</table>
**Summary of Expenditure**

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remuneration costs</td>
<td>£150 869</td>
</tr>
<tr>
<td>Travel &amp; conference attendance costs</td>
<td>£15 352</td>
</tr>
<tr>
<td>Project costs</td>
<td>£47 910</td>
</tr>
<tr>
<td>Administration costs</td>
<td>£11 990</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£226 121</strong></td>
</tr>
<tr>
<td>Deficit</td>
<td>-£2 359</td>
</tr>
</tbody>
</table>
Board of Trustees

ICPCN is thankful for the support and direction voluntarily given by our global Board of Trustees, along with our South African Board, who uphold the work and mission of ICPCN wherever they are in the world. They are:

Ms Sabine Kraft (Chair) Germany
Ms Sharon Baxter (Vice-Chair) Canada (Retired May 2018)
Mr Paul Quilliam (Vice-Chair from May 2018) Australia
Mr Richard Carling (Treasurer - Retired May 2018 and remains a Co-opted Member)
United Kingdom
Mr Michael Palfreman (Treasurer from May 2018), United Kingdom
Dr Zipporah Ali - Kenya
Dr Stephen Connor – USA
Mrs Lynda Gould - China
Ms Dianne Grey – USA
Dr Regina Okhuysen-Cawley – Mexico/USA
Dr Marianne Phillips – Australia
Dr Christina Vadeboncoeur – Canada (Commenced May 2018)
Mrs Zodwa Sithole – South Africa (Commenced May 2018)
Dr Delia Birtar – Romania (Retired May 2018)
Dr/Prof Hanneke Brits - South Africa (Retired May 2018)
Mr Peter Ellis - United Kingdom (Retired May 2018)
Mrs Fatia Kiyange – Uganda (Retired May 2018)
Dr Marli Roberson – Canada (Retired May 2018)
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
- Open Society Foundations
- KrebsAlliance
- The US Cancer Pain Relief Committee
- The European Union through Horizon2020
- The Fondazione Hospice MariaTeresa Chiantore Seragnoli
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)