This year has gone quickly and before we know it we will be enjoying the 3rd ICPCN conference in Durban. Meanwhile as we reflect back on 2017/2018 we do so with gratitude for the ongoing support globally for ICPCN and the development of children’s palliative care. Much has happened within the global agenda including an emphasis on Universal Health Coverage, with palliative care as an integral component, the ongoing move towards the Sustainable Development Goals (SDGs) and the publication of the Lancet Commission: “Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: the Lancet Commission report” including recommendations for further emphasis on children’s palliative care. Alongside this we have seen a strengthening of the voice of direct stakeholders with Lucy Watts, one of Global Ambassadors having the opportunity to meet Dr Tedros, the Director General of the World Health Organization to advocate for palliative care globally.

This year also saw the expansion of our team at ICPCN with the addition of Alex Daniels as our Education Officer. We are extremely lucky to have Alex work with us as she is an experienced palliative care nurse and educationalist and is in the process of completing her Masters in Palliative Care. Alex joined us initially to focus on the e-learning portfolio but is now addressing all aspects of education within ICPCN. As we remain a small team of six of us, we are reliant on working with all of you – our partners, friends and colleagues as we continue to promote and support the development of children’s palliative care globally. We have also been delighted to support Joan Marston in the development of the history of children’s palliative care, supported by the True Colours Trust, and we look forward to hearing more about this as her work continues.

Whilst it is exciting to see the developments in children’s palliative care, we are still aware of the ongoing need to expand provision so that all of the 21.6 million children globally requiring palliative care can access it. Together, we still have a long way to go to achieve this aim. As the ICPCN Strategic Plan 2015-2018 draws to a close we have taken the opportunity to step back and reflect on what has been achieved, where we as ICPCN have achieved what we set out to do, and where we have not yet done so and why? We are also looking ahead to the next 3-5 years as we develop our new Strategic Plan and would like to thank all of you who have been/will be involved in this process. We value your input, and as a network of members from around the world it is important for us to hear your views.

We would therefore like to celebrate all that has been achieved over the last year, reflect on the challenges and look ahead to the next 3-5 years as together we move to develop children’s palliative care globally.

*Prof. Julia Downing*
Our year in review...

April 2017
- ICPCN attended the United Nations Inter-Agency Task Team on Social Protection Annual Meeting
- Meetings with the World Health Organization and UICC in Geneva were held
- Alex Daniels joined the ICPCN Team to work on the e-learning programmes and support ICPCN’s education programme.

May 2017
- ICPCN Board of Trustees Annual Meeting was held
- Focus on children’s palliative care at the European Association of Palliative Care Congress in Madrid, Spain.
- Open Meeting of the EAPC Task Force on Children’s Palliative Care in Madrid, Spain.
- ICPCN participated in the World Health Assembly (WHA) in Geneva

June 2017
- Remote meeting of the African Children’s Palliative Care Network held
- ICPCN team meetings held in Durban, South Africa
- ICPCN team supported the Umduduzi Angel Breakfast in Durban, South Africa
- Training of Trainers course held in Maseru, Lesotho through the project funded by OSISA
- ICPCN conducted training on children’s palliative care in Prague, the Czech Republic
- ICPCN shared experiences at the Cicely Saunders Institute Global Palliative Care Research Day
- The CPC History project commenced

July 2017
- ICPCN participated in a Wales for Africa conference in Cardiff, UK
- ICPCN participated in the Asia Pacific Palliative Care Conference in Singapore, facilitating sessions and workshops on children’s palliative care and research.
- ICPCN participated in the Board Meeting for the Worldwide Hospice and Palliative Care Alliance in Singapore.
- ICPCN Co-Chaired the 8th International Cardiff Conference on Paediatric Palliative Care alongside Cardiff University.
- ICPCN spoke at the Conference on Trauma and the Spirituality of Children and Youth held at UNISA, South Africa.

August 2017
- ICPCN held a training on pain and the use of the ICPCN Pain App with Mildmay Uganda in Kampala, Uganda
- ICPCN had a stand and speak at the Joint Uganda Cancer Institute and Palliative Care Association of Uganda Conference in Kampala, Uganda
- ICPCN taught on CPC at the University of Johannesburg, South Africa.
September 2017
- ICPCN facilitated another week of training on CPC in Prague, The Czech Republic
- ICPCN supported a Global Palliative Care Day on Leadership and Universal Health Coverage held at the University of Edinburgh, Scotland.
- Tweetchat held for Childhood Cancer Month in collaboration with HPCA with Guest Tweeter Dr Julia Ambler, Deputy Director of Umduduzi Hospice Care for Children,
- ICPCN spoke at the Regional Psychosocial Support Initiative (REPSI) conference in Dar-es-Salaam, Tanzania
- ICPCN presented at a seminar looking at A Global Perspective on palliative care from needs to solutions in Bologna, Italy.
- ICPCN representatives went to Lesotho to evaluate the impact of the CPC training programmes that had been conducted in the previous twelve months.

October 2017
- Successful 4th annual Hats on for CPC Day held on Friday 13th October to raise funds and awareness of the need for CPC around the world.
- ICPCN spoke at the Royal Society of Medicine meeting on Global cancer control in low and middle-income countries in London, UK.
- ICPCN shared their experiences with regards to research in low income settings at the International Observatory on End of Life Care Seminar at Lancaster University in the UK.
- ICPCN co-supported a conference on Spirituality in Palliative Care held in both Cape Town and Pretoria, South Africa.
- ICPCN helped to facilitate a 3-day workshop on children’s palliative care at Hospiz Malaysia in Kuala Lumpur, Malaysia.
- ICPCN participated in World Hospice and Palliative Care Day with the theme Universal Health Coverage and Palliative Care: Don’t leave those suffering behind!
- The Lancet Commission report on: “Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: the Lancet Commission report” was launched on 12th October. ICPCN participated in the report as a Co-Author, and were involved in the media and publicity around the launch, focusing on the issues for CPC globally.
- Training of Trainers course held in the Czech Republic and facilitated by ICPCN
- ICPCN supported the Lesotho Ministry of Health to launch their national children’s palliative care programme.

November 2017
- ICPCN presented at the National Symposium of Palliative Care in Kigali, Rwanda
- ICPCN presented at the AORTIC International Conference on Cancer in Africa in Kigali, Rwanda.
- ICPCN spoke at the Emirates Oncology Conference in Abu Dhabi, UAE
- Prof Julia Downing invited to share her Leadership Journey at the Launch of the Emirates Nursing and Midwifery Leadership Society in Dubai, UAE.
- ICPCN presented at the Palliative Care Symposium at Tawam Hospital in UAE.
- ICPCN gave the Keynote speech at Uitnodiging mini-symposium ‘10 jaar Stichting PAL’ in Utrecht, The Netherlands.
- ICPCN attended the All Parliamentary Meeting on Palliative Care at the House of Lords in the UK looking at Global PC issues.

December 2017
- ICPCN participated in Open Society Institute’s Making Change Happen: Strategic Advocacy and Communications for Palliative Care, in Salzburg, Austria.
- ICPCN participated in the MSF Paediatric Days in Dakar, Senegal.
January 2017
• ICPCN attended the Graduation of the BSc Palliative Care students at Makerere University, Kampala, Uganda to celebrate the achievements of the graduates from across the region, some of whom work in CPC.
• ICPCN helped to facilitate a training on palliative care, providing the CPC input, at Camboni College of Science and Technology, Khartoum, Sudan.
• ICPCN were involved in the Inaugural Meeting of PORTAGE Initiative (Paediatric Oncology Roundtable to Transform Access to Global Essentials) held in Sharjah UAE with the leadership, support and collaboration of Friends of Cancer Patients, Sharjah UAE and under the Patronage of Her Highness Sheikha Jawaker Bint Mohammed Al Qasimi.

February 2017
• ICPCN present on Global PC issues at Hospiz Stuttgart Fachtag and visit their new children’s hospice, in Stuttgart, Austria.
• ICPCN supports Tata Memorial Hospital in facilitating some seminars on CPC both in Mumbai and in Delhi, India.
• ICPCN participate in the 25th Annual Conference of the Indian Association of Palliative Care in New Delhi, India.

March 2017
• 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 work 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.

ICPCN Staff 2018

*From left to right: Lorna Sithole (Media & Marketing Officer); Sue Boucher (Director of Communications); Prof Julia Downing (Chief Executive); Busi Nkosi (Director of Advocacy); Barbara Steel (Admin and Finance Manager); Alex Daniels (Education Officer)*
Our year in pictures...
ICPCN is the only global children’s palliative care membership organisation and has both individual and organisational members in 126 countries around the world. We keep our membership connected and informed through our website, the International Children’s edition of ehospice, our social media pages (Facebook, Twitter and Instagram), regular blogs, notices and monthly electronic news bulletins.

All queries received via the website or social media are responded to within 24 - 48 hours and the organisation regularly connects professionals across the world for the purpose of research, training, mentoring, interning and experiential learning opportunities.

Membership
ICPCN membership spans 126 countries with 2002 individual and 395 organisational members. Organisations belonging to ICPCN can be found in the Directory found on our website. In addition, we provide a regularly updated and interactive map of services that we know provide palliative care to children. This assists us to stay informed of the development of services worldwide and enables us to connect members and organisations across the globe, whenever this is required. This map also serves to highlight the gaps in provision.

The ICPCN Website
Our website is the official window to the work we do and is kept relevant with the addition of news, event information and appropriate resources. The calendar of events includes information and contact details for local and international conferences, workshops, study days and training opportunities related to the field. The website signposts pertinent information on certificate courses, diplomas, and post graduate qualifications in children’s palliative care. The resources section links to numerous useful resources for practitioners, including some in languages other than English. In the past 12-month period, more than 32,000 visits have been made to the ICPCN website.

ehospice
The International Children’s edition of ehospice, edited by ICPCN, had a readership of more than 6,000 users throughout the year and has run articles that cover a wide spectrum of news topics from around the world, of particular 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.

Social Media
Our social media is an important avenue that we rely on to share relevant and timely news on children’s palliative care. We’ve experienced a reasonable amount of growth across our social media in this year and our current social media following was:
- Facebook – 10676
- Twitter – 2184
- Instagram – 225

We pride ourselves in sharing engaging content from around the world which will enrich our followers; our social media is the platform we use to share important news, resources and research. We strive to keep our content appealing using videos, graphics, competitions, awareness days, blogs and campaigns. In the past year we have explored the use of paid advertising features across our social media which has yielded positive results, specifically a growth in following and an increase in overall reach.

Hats on for children’s palliative care
‘Hats on 4 CPC’ (#HatsOn4CPC) is an annual campaign where people are asked to wear a hat on the second Friday of October 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.

In its fourth year of running, this year’s campaign was bigger and better than ever, with over 47 events registered in 27 different countries across the globe. Our social media coverage of the campaign increased tremendously with an organic reach of 680,000 on Facebook and Twitter. The total funds raised from the campaign amounted to R23,510.

A beautiful campaign video was created of the children at Sunflower Children’s Hospice in Bloemfontein, South Africa by SupraMedia Productions. This video, as well as other marketing efforts lead to numerous magazine and newspaper features television and radio interviews as well.

3rd ICPCN Conference
Following the success of the 2nd ICPCN Conference in Buenos Aires in May 2016, the ICPCN team were working hard throughout the year on the preparation for the 3rd ICPCN Conference to be held in Durban, South Africa in May 2018. The theme of the conference: Inspiration, Innovation, Integration provides plenty of scope for the presentations and 211 abstracts from 44 countries were submitted for the conference, and reviewed by a scientific committee representing 27 countries.
The conference aims to bring together people from around the world and from all professions working with children with life-threatening and life-limiting conditions and encourages the exchange of knowledge, new and innovative ideas, research and experiences between them. The programme boosts a wide range of international and regional experts on children’s palliative care, including representatives from the World Health Organization, the Kwazulu Natal Department of Health, and speakers from India, the UK, Uganda, South Africa, Portugal, Greece, and Mexico/USA. Experiences will be shared not only by professionals working in the field of CPC, but also through the voices of those receiving or having received care.

Six pre-conference workshops will be held addressing issues such as: children’s palliative care in humanitarian situations, Reaching out to develop a CPC programme; Perinatal Palliative Care, Ethics in CPC, Research in CPC, Difficult conversations in CPC and Managing pain in CPC. We will also be premiering the film ‘Hippocratic’ in South Africa and are delighted that Dr MR Rajagopal, Nobel Peace Prize Nominee is able to join us at the conference.

We have had an amazing Local Organising Committee, made up of representatives from ICPCN along with our local partners, Umduduzi Hospice care for children, Palliative Treatment for Children (PatchSA), the Hospice Palliative Care Association of South Africa (HPCA), the Durban Convention Bureau, the KZN Department of Health and our conference organisers Interactive Hospitality Unlimited. We are grateful to all that they are doing to make this conference a success. As we write this Annual Report we are in the last few weeks leading up to the conference and are looking forward to welcoming people to the beautiful city of Durban and the Elangeni Hotel on the beachfront.
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.

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 Hats of 4 CPC campaign and the annual World Palliative Care Day, with the theme for 2017 being that of ‘Universal Health Coverage: Don’t leave those suffering behind”.

ICPCN works on position statements and advocacy materials for specific events, such as the World Health Assembly, UN high level meetings, etc.

Working with key stakeholders including the bi-lateral organisations e.g. the UN Inter-Agency Task Team (IATT) on HIV Care, Support and Social Protection, and with the World Health Organization on a variety of projects. For example, ICPCN participated and made a video presentation for the meeting of the Commission on Narcotic Drugs which was held in Vienna in September 2017. The purpose of the meeting was to discuss the challenges with regards to the availability of opioids for pain relief. ICPCN is also committed to working with the World Health Organization and has been collaborating with them during this period on the development a handbook: “Integrating Palliative Care and Symptom Relief into Paediatrics: A Guide for Healthcare Planners, Implementers and Managers.” ICPCN has also contributed to another WHO handbook on “Palliative Care and Symptom Control in Response to Humanitarian Emergencies and Crises: A WHO Guide for Planners, Implementers and Managers”. Both of these are due to be published later in 2018. As the Global voice for CPC ICPCN often gets called upon for its input, both by governments, professionals, the media and children and their families. We have been delighted that this year our Global Ambassador Lucy Watts has been able to represent palliative care, and has had the opportunity to meet Dr Tedros, the Director General of the World Health Organization, and speak out for children, young people and adults needing palliative care. She continues to be instrumental in global advocacy for palliative care.

Crucially this year, ICPCN has been involved in the development of the Lancet Commission report on “Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: The Lancet Commission report”. The report was published in October 2017, and ICPCN had an important role in shaping the final report and ensuring that the needs of children and their families were not missed out. The report recommends a further Lancet Commission on CPC and ICPCN is exploring opportunities to lead on this. ICPCN were involved in the lead up to the launch of the commission writing key messages, developing press reports, making advocacy videos and ensuring that the voice of CPC was heard as the report was launched.

ICPCN is also part of Paediatric Oncology Roundtable to Transform Access to Global Essentials (PORTAGE), a group advocating for access to childhood cancer treatment and...
drugs in low and middle-income countries. This group was established in January 2018 and has already collected evidence on drug need and accessibility and established partnerships to help alleviate the problem of poor access to treatment in LMICs.

To create awareness in CPC, ICPCN has developed policy briefs and position papers for various conditions that require palliative care and posted them on its website and distribute them to the relevant disciplines. As part of awareness raising, ICPCN staff visits universities in different countries to give lectures on CPC. Presenting at non-palliative care conferences is also part of the ICPCN strategy to create awareness on the need for CPC integration.

Thus, 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:

**Lesotho**
With funds from OSISA, ICPCN assisted the Lesotho Ministry of Health to develop documents necessary for the implementation of palliative care. These documents included training curriculums and manuals, national guidelines and data capturing registers. Furthermore, ICPCN assisted the ministry in launching the National Children’s Palliative Care Programme on the 13th October 2017. The ICPCN also supported the establishment of the national palliative care association.

**South Africa**
ICPCN has partnered with the Rare Diseases Alliance both at the global and national level in South Africa. ICPCN is part of the committee planning for the conference that will take place in September 2018 in South Africa and the Director of the Rare Diseases South Africa is a plenary speaker at the 2018 ICPCN conference. ICPCN is also a member of the Genetic Alliance of South Africa. CPC forms part of childhood cancer treatment and care and to ensure paediatric oncology professionals do not lose sight of this, ICPCN sits on the Childhood Cancer Network South Africa.

**India**
In partnership with Tata Memorial Hospital in India, ICPCN participated in the in-service education programme the hospital provides to undergraduate and post graduate health care professionals in Mumbai. The programme covered all aspects of children’s palliative care.

**Serbia**
ICPCN was able to visit Serbia and to follow up on some of the training that had previously been undertaken. There is a keenness to develop further CPC within the country but support is needed. ICPCN are looking at how they can provide some ongoing support in this area and work with Belhospice as well as the Ministry of Health and key stakeholders. ICPCN’s Chief Executive was awarded a Visiting Professorship at the University of Belgrade and this will help in forging ongoing links.

**The Netherlands**
The Netherlands CPC organisation ‘PAL” celebrated their 10-year anniversary with the
launch of a new information website for professionals and families – the National Centre of Knowledge and Information for CPC. ICPCN attended the launch and as one of the guest speakers could advocate for the ongoing development of CPC in the Netherlands as well as share the situation globally. Opportunities such as this to advocate for CPC in-countries are important in the ongoing development of CPC worldwide.

Regional Advocacy
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**: To help strengthen and develop more CPC services in Africa, ICPCN in partnership with the African Palliative Care Association (APCA), has established the African Children’s Palliative Care Network. The network consists of members from Malawi, Nigeria, Botswana, Zimbabwe, Rwanda, Sudan, Swaziland, Uganda and South Africa. The role of this is to advocate for CPC within the region and share information where necessary.

- **The European Children’s Palliative Care Taskforce**: This was launched in 2016 and ICPCN are part of the steering committee. The Task Force was able to influence the input on CPC at the EAPC conference in Madrid and following the success in Madrid have managed to ensure there is a track on CPC at the next EAPC conference in Berlin 2019.

- **The Asia Pacific Hospice and Palliative Care Network**: ICPCN was able to support a pre-conference workshop, along with several sessions and workshops on CPC at the APHN conference in Singapore and hopes to be able to continue this support in 2019 in Indonesia

- **Latin America**: ICPCN is planning to collaborate with the ALCP for their next conference in 2019 to support the CPC network within the region. ICPCN had hoped to be able to attend the ALCP conference in 2018 and met with members at the OSI Salzburg meeting in December 2017 and were able to discuss future collaborations.
**Education**

Education is a key component of ICPCN’s work to ensure that all those who require education on children’s palliative care may access it. To facilitate this educational objective, online e-learning courses are offered and face-to-face training programmes are available where possible.

Examples of some of ICPCN’s education activities include:

**Face to face training:**

**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 was discussed.

**India**
In February 2018, ICPCN was invited to participate by Tata Memorial Centre and the Indian Association of Palliative Care (IAPC) in two workshops in Delhi India prior to the Indian Association Palliative Care Conference. These workshops were on ‘The integration of palliative care into paediatric/ neonatal intensive care’ and ‘Nursing Issues in Palliative Care’. Prior to this ICPCN were also invited to participate in workshops on CPC in Mumbai.

**Czech Republic**
ICPCN facilitated a series of training programmes on paediatric palliative care in Prague, in The Czech Republic. CPC training was held in June and September 2017 followed by a Training of Trainers (ToT) course in October. ICPCN were delighted that Maraliza de Haan (Netherlands) and Dr Mike Miller (UK) were able to support the training alongside Prof Julia Downing and Sue Boucher. It has been exciting to see the ongoing development of CPC in the Czech Republic and ICPCN will continue to work with and support the team in Prague.

**Lesotho**
ICPCN continued to provide training in Lesotho, including a ToT course in June 2017. Following on from the trainings provided, ICPCN representatives facilitated focus group discussions in September 2017, in three regions of Lesotho to evaluate the impact of the ICPCN led training courses held earlier in the year.

**China**
Butterfly House requested the use of the translated Mandarin e-learning programmes to be used as a resource for learners undergoing Butterfly House led face to face paediatric palliative care training.
**Uganda**

In August 2017, ICPCN ran a 3-day training programme on the management of pain and the utilisation of the ICPCN Pain App in conjunction with Mildmay Uganda. This was the first training on the use of the App and it enabled some of the initial challenges to be ironed out. Further training is planned in the future.

**The E-Learning Programme**

ICPCN has a dedicated Moodle Platform from which it runs e-learning programmes. E-learning programmes are available for free and participants may join in at any time. Seven children’s palliative care courses are available in a range of languages including English, Spanish, Portuguese, Serbian, French, Mandarin and Czech. Vietnamese and Hindi courses will be made available soon. Course topics include an introduction to children’s palliative care, communicating with children and emotional issues, end of life care and perinatal care and more. See www.elearncpcn.org for details.

To date over 3,000 participants from approximately 124 countries have undertaken the e-learning programmes. Over the period from 1st May 2016 – 30th April 2018, 1,501 participants from 96 countries undertook the elearning programmes including participants from 9 new countries. The following diagram illustrates the professional profile breakdown of these participants.
Over the course of the year:

- **Czech**: Seven Czech courses have been translated, loaded and are active.
- **Mandarin**: Seven Mandarin courses have been loaded, two are active and five are currently under review by subject expert.
- **Hindi**: Two Hindi courses have been loaded and both are under review by subject experts.
- **Portuguese**: Sixth Portuguese course loaded, reviewed and now active. Seventh Portuguese course is undergoing translation.
- **Spanish**: Sixth Spanish course loaded, yet to be reviewed by subject expert.
- **Russian**: Sixth Russian course loaded, yet to be reviewed by subject expert.
- **Vietnamese**: First Vietnamese course is in the process of being loaded.
- **Ongoing work in preparing additional courses for loading.**

Other education and training opportunities included:

- In July, ICPCN facilitated a workshop on CPC at the APHN conference in Singapore.
- In August ICPCN presented a CPC workshop at the UCI/PCAU Conference in Kampala, Uganda.
- ICPCN has advised organisations in different countries with regards to education and training on CPC.
- ICPCN supported some training on CPC at Hospiz Malaysia in October 2017.
- ICPCN is involved, through Prof Julia Downing is supervising BSc, MSc and PhD projects on CPC from around the world.
- 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 theses in this area.
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 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 Fribert and Paula McPoland on this study. Data collection is still ongoing in South Africa but has been completed in the USA and Haiti, and is due to commence in Uganda. Initial analysis has been undertaken and themes identified, along with similarities and differences in the different settings.
- 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 will be involved in this process.
- ICPCN is involved in a study with Edge Hill University looking at issues around transitions. This study was commenced at the end of the period and will be ongoing over the next year or so.
- ICPCN inputted into a palliative care needs assessment in the Rohinga Refugees in Bangladesh, in conjunction with PALCHASE.
- 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. This involved defining a “pioneer” in this context, where it was taken to mean someone whose innovative work has influenced the development of CPC; while also recognising those who had the vision to begin early programmes that in themselves were - and often still are - excellent but were not as influential. 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. This study is also looking at factors in the global environment as well as ground-breaking research with children that supported the development of the field. Certain themes came through unexpectedly and these will be part of further collaborative study that will look at country, regional and global development past the time of the early pioneers. We are fortunate in having so many of the early pioneers to interview which shows that the field of children’s palliative care is relatively new and constantly evolving.

Dissemination

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

- 15th World Congress of the European Association for Palliative Care – Madrid – May 2017
- 8th International Cardiff Conference in Paediatric Palliative care – July 2017
- Conference on Trauma and the Spirituality of Children and Youth (UNISA) – July 2017
- 12th Asia Pacific Hospice Conference 2017 – July 2017
- UCI-PCAU Joint International Conference on Cancer and palliative Care – August 2017
- REPSSI (Regional Psychosocial Support Initiative) conference in Tanzania – September 2017
- A Global perspective on palliative care: From needs to solutions, Bologna – September 2017
- International Observatory on End of Life Care Seminar, Lancaster University – October 2017
- Spirituality in Palliative Care Conference Cape Town - October 2017.
- The AORTIC International Conference on Cancer in Africa – November 2017
- The Year of Giving – Innovation in Cancer Care. Emirates Oncology Conference. Abbu Dhabi – November 2017
- Palliative Care Symposium. Tawam Hospital. United Arab Emirates – November 2017
- Uitnodiging mini-symposium ‘10 jaar Stichting PAL’ Utrecht – November 2017
- MSF Paediatric Days. Dakar 2017. Senegal – December 2017
- Hospiz Stuttgart Fachtag – February 2018
- Indian Association of Palliative Care Pre-conference workshops – February 2018
- 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

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

on Cancer and Palliative Care and the 7th Palliative Care Conference, 24–25 August 2017, Kampala, Uganda. ecancer 11;790.


Finance

An extract from the draft consolidated Financial Statements for the year ended 28 February 2018 is given below.

Overall income for the year amounted to £278,761. 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 £244,766 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. We would like to thank the following for their support this year:

- Open Society Foundation
- US Cancer Pain Trust
- True Colours Trust
- Krebsallianz
- Heb Ffin
- Open Society Initiative for Southern Africa

A breakdown of income and expenses for the financial year March 2017 to February 2018 is shown in the charts below:

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<th>FUNDER</th>
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<td>True Colours Trust</td>
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</tr>
<tr>
<td>True Colours Trust: Education</td>
<td>£9 450</td>
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<tr>
<td>True Colours Trust: History of CPC</td>
<td>£10 000</td>
</tr>
<tr>
<td>Open Society Foundation</td>
<td>£107 419</td>
</tr>
<tr>
<td>Open Society Initiative for Southern Africa</td>
<td>£19 998</td>
</tr>
<tr>
<td>Krebsallianz</td>
<td>£16 868</td>
</tr>
<tr>
<td>United States Cancer Pain Relief Committee</td>
<td>£58 358</td>
</tr>
<tr>
<td>Heb Ffin</td>
<td>£5 000</td>
</tr>
<tr>
<td>General Fund - Unrestricted</td>
<td>£24 462</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>£288 761</strong></td>
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</table>
Summary of Expenditure

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff costs</td>
<td>£154 404</td>
</tr>
<tr>
<td>Travel costs</td>
<td>£22 704</td>
</tr>
<tr>
<td>Direct project costs</td>
<td>£47 384</td>
</tr>
<tr>
<td>Office &amp; admin costs</td>
<td>£20 274</td>
</tr>
<tr>
<td>TOTAL</td>
<td>£244 766</td>
</tr>
</tbody>
</table>

ICPCN Annual Report 2018

ICPCN INCOME RESOURCES 2018

ICPCN EXPENDITURE FOR 2018

- Remuneration Costs
- Travel & Conference attendance
- Project Costs
- Administration Costs
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
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Dr Zipporah Ali - Kenya
Ms Sharon Baxter - Canada
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Linda Ganca - South Africa
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Dr Anna Garchakova – Belarus (Retired May 2017)
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
- Open Society Initiative of Southern Africa
- Heb Ffin
- KrebsAlliance
- The US Cancer Pain Relief Committee
The ICPCN is administered from within South Africa.
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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)