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The Need

Palliative care for children represents a special, albeit closely related field to adult palliative care. The World Health Organization’s (WHO) definition of palliative care appropriate for children and their families is as follows:

*Palliative care for children is the active total care of the child’s body, mind, and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child’s physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, community health centres and even in children’s homes.*

The need for accessibility to children’s palliative care varies globally, with differences seen between countries and regions. Most children (98%) needing palliative care live in low- and middle-income countries.

The development of quality children’s palliative care services has been a neglected area and often lags behind that of palliative care development for adults. The International Children’s Palliative Care Network (ICPCN) estimate that worldwide 20.1 million children (0-19 years of age) can benefit from palliative care with >8 million requiring specialist service provision.

Children and their families have specific and intensive palliative care needs that can easily be overlooked because the absolute number of paediatric patients is low compared with adults.

As a central repository for information relating to children’s palliative care 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 children’s palliative care.

More information about children’s palliative care can be found HERE.

>21 million children

Our research reveals over 21 million children around the world would benefit from quality palliative care

8 million children

At least 8 million children out of the 21.1 million need more specialised services

95% of children globally

Who need palliative care, have limited to zero access to such care
How ICPCN is working to meet the need

COMMUNICATIONS
The provision of up-to-date information is one of ICPCN’s core functions. This is accomplished through a variety of means including this website, ehospice, our social media platforms, reports and regular membership alerts and monthly newsletters.

ADVOCACY
ICPCN aims to provide the global voice for children’s palliative care and to advocate for the rights of children to receive the palliative care they require.

RESEARCH
ICPCN believes that research and its dissemination is an important component of the development of children’s palliative care globally. Increasing the evidence base is vital to improve care provision, along with service delivery, education and advocacy.

EDUCATION
ICPCN recognises the importance of making training of children’s palliative care accessible and affordable to all who need it. Thus, providing both face-to-face and online training to care providers around the world.

STRATEGIC DEVELOPMENT
ICPCN supports the strategic development of children’s palliative care services worldwide through equipping, empowering and supporting network members.

ICPCN’s vision is 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. We know the difference that palliative care can make and want to ensure that every child and their family that needs it will have access to palliative care regardless of where in the world they live. Children such as Angeline, whose story we tell here and in more details on our website.

Angeline’s Story
12-year old Angeline (name changed) was living with her mother, her 14-year-old brother and her grandmother. Angeline had a normal life until she was diagnosed with cancer 3 years ago. She was one of the children provided palliative care from the Golden Butterflies Children’s Palliative Care Foundation in Chennai, India.

Angeline was determined to not let cancer overtake her. She proved that she was more powerful than cancer. Despite her undying resilience, there was a shadow of loneliness visible in her because her world was confined within the four walls if her house and she didn’t have friend. The Golden Butterflies team decided to change her little world having seen the wonder of the arts, and her joy knew no bounds when she received a magic kit from them. She and her brother were thrilled to make different art from the kit and as they were exploring their creativity, we saw the shadow of loneliness and darkness fade away. The warmth and care she felt from the team made her brim with positivity. Sadly Angeline passed away but the palliative care provided ensured she lived her life to the fullest and with no regrets and unfilled dreams. Currently, bereavement support is being provided to the family. The words of Angeline’s mother stands as a testimony to the power of palliative care. “I couldn’t imagine this dreadful journey of cancer without your presence and financial support. My own family, including my husband, abandoned us because of my daughter’s diagnosis but your team filled that gap and you not only gave Angeline the support needed but to me and my son also to lean on.”

You can read Angeline’s and other children’s stories on our website.
ICPCN’s 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. We fulfil this mission 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.
Message from ICPCN’s Chief Executive and Board Chair

The need for children’s palliative care globally is huge. An estimated 21.2 million children need access to palliative care, with 8 million of those needing specialised care. Yet we know that the majority of those in need have limited or no access to such care, thus children and their families around the world are suffering needlessly.

This is a human rights issue, and is not good enough. We know how to manage pain and symptoms, to care for children in a holistic manner – body, mind and spirit, and how to provide palliative care for them and their families in different settings – at home, in the community, in the hospital and in hospices – so why is it that so many still can’t access such care? How can we make a difference to the lives of these children and their families? What has been the impact of our work as ICPCN and how can we overcome ongoing challenges to care provision?

Measuring the impact of an organisation such as ICPCN can be a challenge as our work has a global remit, much of what we do is in collaboration with others, and bringing about sustainable change and developments can take many years. Yet at ICPCN we are committed to ensuring that all children living with a life-limiting or life-threatening condition and their families will have seamless access to palliative care regardless of how old they are, their gender, their race, their religion, what condition they have, or how long they have to live.

Whilst the majority of hands-on care is undertaken by our colleagues around the world, ICPCN believes that through our communication, advocacy, research, education and strategic development we make a difference to the provision of palliative care globally. ICPCN is recognised as the global leader for children’s palliative care. With a globally renowned expert leadership, a wealth of resources, membership of >4,300 individual and >430 organisations from at least 140 countries, we believe that we are uniquely placed to support the ongoing development of children’s palliative care worldwide.

Never before has there been such strong global commitment for the development of children’s palliative care. Will you join us as we harness this commitment and strive to ensure access to palliative care for all neonates, babies, children and young people in need around the world?

Prof. Julia Downing
ICPCN Chief Executive

Mike Palfreman
ICPCN Board Chair
Our Impact

The ICPCN is the only global organisation working to improve access to palliative care for the more than 21 million children worldwide who need it. This Impact Report, our first, charts our progress in fulfilling that mission.

It explains what we do, and how we do it. It highlights some of our most important work, demonstrating the impact we’ve had as the world leader in children’s palliative care. Through our network, ICPCN is uniquely placed to advise, educate and support on best practices in children’s palliative care at a national, regional, and international level.

We aim to achieve our mission by raising awareness of children’s palliative care, advocating for the global development of children’s palliative care, expanding the evidence-base and sharing expertise, skills and knowledge. We do this through five strategic focus areas:
We are committed to improving channels of communication and instituting new ways of setting up a two-way flow of information and understanding. Members, along with those looking for information on children’s palliative care, can access the information and resources that they need, are kept up to date on developments, and are linked in with other members as appropriate.

As a network, membership is important and it has been exciting to see ICPCN’s membership grow, both in terms of numbers, and also countries represented. Membership remains free in order to ensure that all those working in the field are able to become members.

Thus, the provision of up-to-date information is one of ICPCN’s core functions. This is accomplished through a variety of means including the website, ehospice, our social media platforms and regular membership alerts and monthly newsletters.

**Newsletter**
- Monthly newsletter sent out to all ICPCN members
- News from within ICPCN, global updates and information on children’s palliative care
- Other news sent out as appropriate
- On average 30-40% of recipients open the newsletter

**Website**
- Averages >3,500 visits every month
- Sharing information, news and resources
- Some materials available in a range of languages and expanding this gradually

**ehospice – International Children’s Edition**
- Articles published each week and shared within the ehospice weekly newsletter
- Articles published from around the world
- >50% returning visitors

**HatsOn4CPC campaign**
- 2nd Friday of October every year
- An established activity in the annual calendar
- An average of >2 million twitter impressions
- Activities undertaken around the world – >50 countries
- Toolkit shared via the website

**Social Media @ICPCN**
- Facebook - >12,930 followers
- Twitter - >3,910 followers
- Instagram - >770 followers
- LinkedIn - >420 followers
- YouTube - 161 subscribers
The information from the ICPCN newsletters and website keeps Kawempe Home Care (KHC) updated on important events like the commemoration of International Childhood Cancer Day, World Hospice and Palliative Care Day, the “Hats on for Children’s Palliative Care” awareness campaign, upcoming palliative care conferences, etc. This information has enabled KHC to participate in many of these events. – Kawempe Home Care Kampala, Uganda

**Hats on for Children’s Palliative Care #HatsOn4CPC**

#HatsOn4CPC is our campaign to raise awareness globally of children’s palliative care. On the second Friday of October, people from all walks of life wear a hat to work or school to raise awareness for children’s palliative care. Photos are posted on social media using the hashtag #Hatson4CPC. ‘Hats on 4 CPC’ events are hosted around the world. In its 9th year, the 2022 HatsOn4CPC campaign saw over 120 events registered on the HatsOn4CPC map across the globe with many more events also taking place. We are excited to mark our 10th year of #HatsOn4CPC this year, on Friday 13 October 2023.

**Resources**

We are committed to providing information on available resources related to the field of children’s palliative care. [Links to theses resources are on our website](#). We will endeavour to keep these resources updated.

If you have a relevant resource that you think we should have links to on our website please do send an email with the information to communications@icpcn.org. Please note that only resources related to children’s palliative care will be included in our resources section.
In early 2023 we launched our new branding and website.

Our Logo
Within the logo we have used the image of the sun:

• Symbolising hope with the bright orange sun which rises and sets every day so also symbolising the circle of life.

• Each morning the sunrise gives people hope for the new day and the sun unites us, brings us together, and symbolises equity as we all see the same sun regardless of where we live.

• The sun is universal in nature, reaching across cultural, religious, and spiritual belief systems.

Our website
ICPCN aims to provide a global voice for children’s palliative care and to advocate for the rights of children to receive the palliative care they require. It is important for us to make information regarding children’s palliative care easily accessible to everyone across different platforms, especially the website. We hope that you will find our new website useful and simple to navigate, while at the same time being able to access information on ICPCN’s impact, important research, news items, stories, events, and a wide range of resources. Thousands of users visit the ICPCN website on a monthly basis.

Thanks
Our new website would not have been possible without the support and generosity of Wild in Art who funded this. They have made this huge step possible and afforded ICPCN the opportunity to rebrand and develop the new website and logo. We would also like to thank Rob Brannon from Rob Designs who worked with us on the branding along with Theresa Wilds, and the team at Cornerstone Design & Marketing for all their hard work, patience and support in developing the website.

We hope that you like our new look as much as we do and look forward to your ongoing contributions to the stories, news items, events, resources, HatsOn4CPC celebrations and much more.
We have played a key part in the ongoing development of children’s palliative care around the world. Since ICPCN started, we have been mapping the provision of children’s palliative care services – these maps show the development of children’s palliative care between 2005 and 2019 with an updated map for 2023 in progress.

We work in collaboration with the global palliative care organisations i.e.: the Worldwide Hospice Palliative Care Alliance (WHPCA), the International Association of Hospice Palliative Care and Palliative Care in Humanitarian Aid Situations and Emergencies (PallCHASE); the regional palliative care organisations i.e.: the African Palliative Care Association (APCA), the European Association of Palliative Care (EAPC), the Asociacion Latinoamericana de Cuidados Paliativos (ALCP), the Asia Pacific Hospice Palliative Care Network (APHN); and national organisations in undertaking advocacy activities, messaging, commenting on documents/policies etc with ICPCN taking the lead and being the voice for children’s palliative care.

ICPCN also takes the lead in advocating for palliative nursing and has been involved a range of advocacy activities with international and regional nursing organisations including: the International Council of Nurses, the International Society of Nurses in Cancer Care (ISNCC), the Global Power of Oncology Nursing (GPON), the International Society of Paediatric Oncology (SIOP) Nursing Group, and the WHO GICC nurses group. Together with St Christopher’s Hospice we organised a successful Pioneering Nurses in Palliative Care conference in 2021 with 90 nurses attending from 30 countries. One attendee said “Brilliant event…. Fantastic array of speakers, enormously stimulating and inspiring”. Another conference is planned for May 2023.

We have contributed to a range of reports, documents and policies over the past few years, ensuring that the voice of children’s palliative care is heard. Many of these can be found on the ICPCN website.
Advocating for children’s palliative care in Ghana

ICPCN has been working with World Child Cancer, the Ministry of Health, Ghana Health services, Korle Bu Teaching Hospital, and Komfo Anokye Teaching Hospital on a needs assessment and situational analysis of children’s palliative care in Ghana. As part of this a stakeholders’ meeting was held in Accra in January 2023. This was an important opportunity to advocate for the development of children’s palliative care across Ghana, bringing together key stakeholders. Advocacy is ongoing as the study is progressing and there are plans for further advocacy activities later in the year.

Palliative Care- Celebrating Nurses’ Contributions

Nurses play a key role in the provision of palliative care globally, and during the International Year of the Nurse and Midwife in 2020, we wanted to recognise this and celebrate their work. As we work to continue developing and strengthening palliative care, we have had the privilege of meeting nurses around the world working in the field, some who are newly qualified and full of enthusiasm, others who are nearing the end of their careers and are keen to pass on their knowledge and skills. This report, highlighting the work of 27 nurses from around the world, is a celebration of the pivotal role of nurses in palliative care across the globe. We hope that it will also serve as an inspiration to policymakers, health care administrators, and managers to support nurses so they can have a more prominent voice in health policymaking, education, and care provision.
Generating and utilising the evidence base on children’s palliative care is vital for the work that ICPCN undertakes. Sometimes we take part in a research project run by others and on other occasions we are responsible for implementing research or signposting members to important studies. The areas of focus for our research activity are broad encompassing a wide range of issues.

Areas of Focus for ICPCN’s Research Activities

We undertake research in collaboration with a wide range of organisations around the world, including academic organisations, hospitals, Charities and non-governmental organisations (NGO’s). Information on collaborators and partners can be found on the ICPCN website.

“Our collaboration with ICPCN has been essential in advancing our mission of defining the state of palliative care for children around the world and addressing patient and family suffering. The global network, the deep knowledge, and the expertise of the members of ICPCN have exemplified the importance of how an interdisciplinary team can effectively and empathetically address the needs of our patients and families. The impact of this relationship will continue for many years to come.”

Dr. Michael McNeil, Director St Jude Global Palliative Care
Due to the COVID-19 pandemic we have not held our own conference in the last few years – however we have collaborated with others around the world to support their conferences, such as APCA, EAPC, the Palliative Care Association of Uganda (PCAU), the Indian Association of Palliative Care (IAPC) and GPON.

A key part of our role is the dissemination of research and information on children’s palliative care through the publication and presentation of papers. We are often invited to give keynote or plenary presentations at a wide range of conferences and also submit abstracts for presentation.

Due to the COVID-19 pandemic we have not held our own conference in the last few years – however we have collaborated with others around the world to support their conferences, such as APCA, EAPC, the Palliative Care Association of Uganda (PCAU), the Indian Association of Palliative Care (IAPC) and GPON.

ICPCN supports the Pre-conference workshops on CPC in Bengaluru, India. A workshop on children’s palliative care was held prior to the Indian Palliative Care Conference (IAPCON 2023) in February 2023, focusing on palliative care for children with common non-oncological conditions and the use of the serious illness conversation guide. The workshop was organised by the Pain Relief and Palliative Care Society (PRPCS) Hyderabad, Two World Cancer Collaboration, the Cipla Foundation and the International Children’s Palliative Care Network (ICPCN). Over 40 participants attended the workshop including doctors, nurses, social workers, psychologists and other members of the multidisciplinary team from across India, Nepal and the Philippines. One participant commented: “This workshop has inspired me to improve the provision of palliative care in my hospital.”

“This workshop has inspired me to improve the provision of palliative care in my hospital.”
ICPCN supports the VI NIPPEL International Meeting in Brazil.

The major impact for children’s palliative care in the last year was the creation of an instrument to talk about palliative care, death and grief with children and families. We had the opportunity to train schoolteachers, health professionals, families and use this tool with children. Then this year we had the honour to have Prof Julia Downing, Chief Executive of ICPCN, speaking about the topic: “Global considerations for advancing palliative care policies: Equity and Diversity” in our International Meeting with the central theme “Advances in Family Care and Research in Palliative Care for Sustainable Development”. We had 200 participants from all around the world.

Prof. Dra. Regina Szylit, University of Sao Paulo

In 2020 Springer published “Children’s Palliative Care: An International Case-Based Manual” - a book which we edited and collaborated with authors from around the world. It was the result of several years hard work and the handbook aims to enable individuals working in children’s palliative care globally to learn through engaging real-world cases. Through a clinical case based resource that is globally relevant and accessible to those working in CPC. The book draws on case studies from around the world that reflect the key issues and elements of CPC. Paul Quilliam, Past Chair of ICPCN wrote “All involved in bringing this rich resource together should be immensely proud of this publication and the contribution it will make to a very dedicated global CPC community.” We are currently working on another book focusing on children’s palliative care nursing due for publication in 2024.

A list of papers published by ICPCN can be found on the website.

“All involved in bringing this rich resource together should be immensely proud of this publication and the contribution it will make to a very dedicated global CPC community.”
**Education**

Education and training of health care workers is fundamental for children and families in need to access high quality Children’s Palliative Care services across the globe and is a core component of the WHO conceptual model for palliative care. Recent travel restrictions, imposed by the global pandemic, have necessitated a shift from face-to-face education to virtual learning with a range of opportunities to develop online children’s palliative care expertise becoming more readily accessible.

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<tr>
<th>Face-to-face training</th>
<th>E-learning</th>
<th>Webinar Participants</th>
<th>Other virtual training</th>
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<td>&gt;1,400 participants</td>
<td>&gt;8,600 participants</td>
<td>&gt;2,800 attendees</td>
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<td>&gt;30 countries</td>
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<td>13 languages</td>
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**E-learning**

In 2021, we proudly celebrated 10 years of online learning with nine short courses addressing a range of CPC topics currently available in 14 languages. Courses are endorsed by the University of South Wales and freely available on the ICPCN e-learning platform.

Our e-learning programme has made considerable strides since its inception > 10 years ago with over 8,600 users representing 191 countries from all six WHO geographic regions currently enrolled on the site. The large increase in registrations in the past year emphasises the importance of, and need for, our e-learning programme. ICPCN courses are available in a range of languages, these include English, French, Portuguese, Spanish, Mandarin, Dutch, Czech, Serbian, Russian, Vietnamese, Farsi, Bengali, Hindi and Malay.

New courses currently under development include the completion of the course on “Children’s Palliative Care in Humanitarian Settings” in partnership with PallCHASE and an “Advanced course on Neonatal Palliative Care” in partnership with the Neonatal Palliative Care Project funded by True Colours Trust.

For more information please click here.
Partnering with the ICPCN to develop a new palliative care e-learning course for humanitarian health workers, has allowed us to leverage the expertise and global reach of the ICPCN and ensure that the course meets the needs of health workers in the field. The ICPCN has also been an integral teaching partner in the Pediatric Palliative Care Fellowship program of Two Worlds Cancer Collaboration. Paediatricians in this program benefit from learning, interaction, and connections with global palliative care leaders such as Professor Julia.

– Megan Doherty – PallCHASE and Two Worlds Cancer

E-learning courses available

- Introduction to children’s palliative care
- Pain assessment and management
- Communicating with children and other emotional issues
- Child’s development and play in children’s palliative care
- Grief and bereavement in children’s palliative care
- End of life care in children’s palliative care
- Neonatal palliative care: An Introduction
- Symptoms other than pain
- Adopting a children’s palliative care approach to the COVID-19 Pandemic
- Children’s palliative care in humanitarian settings

Individual Registrations Per Year

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E-learning participants

- Nurse: 30.4%
- Doctor: 6.9%
- Councillor: 8.3%
- Social Worker: 10.9%
- Teacher: 11.1%
- Religious Leader: 5.1%
- Other: 17%
- Other (Please specify): 6.9%
- N/A: 0%
Feedback from Kenya

It has been a long journey for me doing the course as have had to do it in middle of treatments and also caring for a child with cancer too but every time I opened the learning portal I could not stop. The mentors are truly organised and the information is clear and easy to understand. I am grateful to ICPCN for giving us this opportunity to learn and fulfil my wish on learning about children’s palliative care but I could not afford the fee for other courses. It has helped me a lot in my line of work because I deal with kids battling cancer and other life-limiting illnesses. I will forever remain grateful. Thank you. – Catherine Wambugu

The recording (of the webinars) has assisted some of us to follow up to date at the same time handling the ICPCN e-learning. I appreciate as it helps also some of us who could not have gotten an opportunity if fees was instituted. You have helped many and keep same spirit of work. – Andrew Adek

Webinars

During the pandemic ICPCN, in collaboration with WHPCA, IAHPC and PallCHASE developed a series of briefing notes on palliative care in the COVID-19 pandemic, and hosted a series of webinars linked to the briefing notes. Following this, in collaboration with WHPCA and IAHPC we hosted a series of webinars linked to the hand book “Children’s Palliative Care: An International Case-Based Manual”. Once these webinars had finished we decided, based on participant feedback, to continue with our monthly webinar series, held on the 3rd Thursday of every month. These regular monthly webinars include presentations by the authors followed by a panel discussion that integrates questions from the audience. To date >2,800 participants have attended our webinars with the panel and audience covering a wide global reach representing diverse resource settings and geographic locations.

Face-to-face training

To date we have conducted face-to-face training for >1,400 participants from >30 countries. Whilst face-to-face training has not been possible during the pandemic we have conducted tailor made programmes on children’s palliative care virtually, such as: the children’s palliative care nurse leadership fellowship programme, funded through the Burdett Trust in collaboration with the University of Edinburgh and the Palliative care Education and Research Consortium in Uganda; and for participants in Iraq from Baghdad and Basra funded by the WHO through the GICC. Face-to-face training has recommenced, and we are excited to be meeting in person once again.

Thanks a lot for this opportunity.....I’m looking forward to the next session..... It is important to know more about palliative care because really we have poor knowledge about such important issues....... There is unavailability of many medications and facility for non-medical management, therefore to apply the principles of palliative care is difficult but we will do our best with the available simple facilities....... We have a lot of challenges but we will work hard to get rid of them......Many thanks for these comprehensive lectures and discussion...... We will start with a small team, slowly growing, regular assessment, regular meetings, finding our weaknesses, talking about morphine etc. I think this is a good start..... We feel we are more committed and the time is right to develop children’s palliative care here in Iraq.

Participants attending the children’s palliative care training in Iraq.
EPEC-Paediatrics Training

We are delighted to be partnering with the EPEC-Paediatrics team (Education in Palliative and End-of-Life Care) to extend the reach of education in children’s palliative care. ICPCN staff have been trained as EPEC trainers and have been involved in the course in San Francisco, Memphis, Uganda and virtually. We also teamed up with St Jude Global to provide scholarships for participants for low- and middle-income countries to attend EPEC courses.

“Partnering with ICPCN on our global EPEC-Paediatric efforts have allowed us to touch people around the world in an unprecedented way as we advocate for children’s palliative care globally. Without ICPCN’s help in recruiting future leaders to join the EPEC-P programmes and contributing to the teaching, we would not have been able to have made such a large impact this year.”

Dr Justin Baker and Dr Stefan Friedrichsdorf. EPEC Paediatrics

The EPEC-Paeds Train the Trainer Programme relieved my stress, revised my energy, and encouraged me to develop children’s palliative care in Vietnam. It was a fascinating opportunity to learn from world-leading children’s palliative care experts. The children’s palliative care session was full of knowledge and skills, which helped affirm and improve the services I have developed. The massage therapy session opened a fun and practical way to approach patients and caregivers, and overcome the “end-of-life care taboo” in palliative care. Besides, I made friends with many classmates who inspired me with their fabulous jobs. Above all, the community we created together after the course eliminated the loneliness in my journey and kept me confident about the development of children’s palliative care worldwide.

Dr Huyen Bui, Director, Palliative Care Department, City Children’s Hospital, Ho Chi Minh City, Vietnam
Mapping of education programmes

As part of our work with the WHO on children’s palliative care training in Iraq, we undertook a review of children’s palliative care training programmes globally. We initially reviewed 114 courses from around the world – 25% of which were specialist courses and 75% generalist courses. Of the courses reviewed 31% were found in the EURO region and 26% in AMRO. Similarities were found in the indicative content of courses around the world, with most courses having some aspects that makes them unique. Further work on mapping education programmes is planned for the coming year.

Evaluation of ICPCN’s education programme

An evaluation of our education programme was conducted during 2021 with participants who had enrolled in face-to-face and / or e-learning training programmes over a period of 10 years (2011 till 2021). The aim of this evaluation was to assess the impact of our face-to-face and online courses and to shape future improvements in both course content and presentation. 5,165 evaluations were distributed, and 613 (11.85%) responses were obtained via Survey Monkey. The evaluation showed considerable knowledge gain in children’s palliative care among 91% of respondents, skills gain at 88%, positive change in attitude 86%, and improvement in clinical practice at 84%. The main outcome of both the online and face-to-face education initiatives was a positive impact in terms of developing further support services in children’s palliative care.

Kawempe Home Care has benefited a lot from the ICPCN programmes in many ways and these include:

1. The educational programmes on the ICPCN website have expanded the knowledge and skills of our palliative care nurse and clinical officer in caring for children with cancer holistically that is physically, psychologically, emotionally and spiritually an important aspect in alleviating the children’s distress.

2. The ICPCN online educational programmes i.e., webinars and website information have helped me to educate families and caregivers of children with cancer about the myth and misconceptions attached to cancer that hinder them from seeking medical care and hence leading to delayed diagnosis or death. This has changed their thinking and improvement in seeking for medical care for their children, and some caregivers have become advocates for cancer treatment in their villages. - Nkurunziza Diana M&E Manager

Kawempe Home Care, Uganda
Strategic Development

Supporting the development of children’s palliative care services worldwide is a core component of our work, although how we do it and the support that we give will vary. This is a cross-cutting issue and an essential component of ICPCNs work.

Through our work we seek to empower and equip those wanting to establish children’s palliative care services around the world. Whilst we currently are not in a position to offer funding, though we hope to be at a later date, we provide advice and comprehensive resources and connect organisations and children’s palliative care champions for mutual learning. We also support the development of centres of excellence in strategic locations. We provide technical assistance in the provision of all aspects of children’s palliative care service development, drawing on the expertise of our members as appropriate.

### Examples of strategic development

<table>
<thead>
<tr>
<th>Country</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>HONG KONG</td>
<td>Supporting the work of the <a href="#">Children’s Palliative Care Foundation in Hong Kong</a> since 2018 as part of the Governing Committee of the Foundation.</td>
</tr>
<tr>
<td>INDONESIA</td>
<td>Supporting the work of <a href="#">Rachel House</a> as they develop children’s palliative care services in Jakarta and advocate for children’s palliative care service development across the country</td>
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<tr>
<td>KENYA</td>
<td>Working with PallCHASE, the <a href="#">Kenya Hospice and Palliative Care Association</a> (KEHPCA) and <a href="#">Two Words Cancer Collaboration</a> to support the development of children’s palliative care in Kenya and East Africa</td>
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<tr>
<td>ITALY</td>
<td>Supporting the team of the Treehouse Children’s Hospice in Bologna, Italy.</td>
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<tr>
<td>IRAQ</td>
<td>Training the teams and supporting the development of children’s palliative care in Iraq</td>
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<tr>
<td>SERBIA</td>
<td>Training and supporting the development of children’s palliative care through <a href="#">Belhospice</a></td>
</tr>
<tr>
<td>CHINA</td>
<td>Forming partnerships and supporting the work of Butterfly Children’s Hospice, the <a href="#">Chinese Nurses Association</a>, <a href="#">Hunan Children’s Hospital</a>, the ISNCC, the APHN, and St Jude Global.</td>
</tr>
<tr>
<td>GHANA</td>
<td>Working with World Child Cancer, the Ministry of Health, Ghana Health Services, Korle Bu Teaching Hospital, and Komfo Anokye Teaching Hospital on a needs assessment and situational analysis of children’s palliative care in Ghana, with the aim of making recommendations and supporting the ongoing development of children’s palliative care in the country.</td>
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</tbody>
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[Children’s Palliative Care Foundation in Hong Kong](#): [Link to the Children’s Palliative Care Foundation in Hong Kong]

[Rachel House](#): [Link to Rachel House]

[Kenya Hospice and Palliative Care Association](#): [Link to Kenya Hospice and Palliative Care Association]

[Two Words Cancer Collaboration](#): [Link to Two Words Cancer Collaboration]

[Belhospice](#): [Link to Belhospice]

[Chinese Nurses Association](#): [Link to Chinese Nurses Association]

[Hunan Children’s Hospital](#): [Link to Hunan Children’s Hospital]

[ISNCC](#): [Link to ISNCC]

[APHN](#): [Link to APHN]

[St Jude Global](#): [Link to St Jude Global]
“Working with ICPCN has been critical as we have been growing our network of Humanitarian Health Care workers in East Africa, through Project ECHO facilitated by PallCHASE, KEHPCA and Two Worlds Cancer Collaboration. Prof. Julia Downing has been a committed faculty member since 2022, speaking to our audience (over 150 individuals over the last 2 years) during the course about Children’s Palliative Care in Humanitarian Settings. We use Case Based teaching as a method of learning, and Prof. Julia has brought engaging situations including children with palliative care needs leading to rich discussions and times for questions from the group.

In 2023, we applied for a large grant in Kenya, with KEHPCA, to improve access to Children’s Palliative Care. With the support of Prof. Julia, of ICPCN, we were able to put forward a strong application. We wait in anticipation to hear if we will receive the grant and move forward with the vision of the project. Thanks ICPCN and Prof. Julia for your ongoing support in East Africa and in particular Kenya.” - Erin Das, PallCHASE

ICPCN’s Global reach

As an international organisation working globally it is important to review our global reach. A review of our membership and education activities up to mid 2022 showed that we are reaching individuals and organisations in 191 countries plus many of the different small islands in the Pacific and the Caribbean. The analysis was undertaken of 11,000 individuals, (out of a current 15,300).
ICPCN is a champion of advocating and advancing children’s palliative care worldwide. When I think of the partnership and relationship between The Rocking Horse Project and ICPCN, I picture one of a parent and child with ICPCN providing guidance, leadership and lending a helping hand along a mostly unexplored and lonely road. ICPCN is a support and mentor to not only The RHP, but to many other organisations worldwide involved in children’s palliative care. From their updated, informative website, to webinars on current affairs in children’s palliative care and providing advice or assistance when one reaches out to them, ICPCN is the pioneer in CHILDREN’S PALLIATIVE CARE.

The RHP has valued the impact that ICPCN is continually making and the growth that they have undergone is inspirational. Having to rely on donations, ICPCN though enduring tough times, has not stopped fulfilling their core mission and moving forward. The RHP staff have developed close friendships with the current and previous ICPCN team. With NGO’s like ourselves, the staff component is relatively small as one tries to make the most use of the available resources, this includes human resources. We have learned to seek the assistance of human resources of other organisations where we lack or need guidance. ICPCN has provided that expertise. One example is the RHP logo; we had it designed, but it lacked high definition resolution qualities. A staff member from ICPCN assisted in developing the logo into one that can be used for multiple applications and marketing techniques. It is vital that despite being a small organisation or an NGO that relies fully on donations, we maintain a visually good reputation and that our marketing is effective.

When Covid-19 disrupted the way we do life and work, ICPCN rose to the occasion and implemented strategies of change and reaching out to others to ensure that CHILDREN’S PALLIATIVE CARE continued. Their book on CHILDREN’S PALLIATIVE CARE: An International case based manual was released and from the book, a series of webinars held every month since mid-2021 have taken place and continue to this year. The RHP has been fortunate to have attended these sessions. The sessions have been so relevant and needed during this time of the Covid pandemic. One can become so overwhelmed during this time and to ‘think out of the box’ seems like an impossible task. ICPCN has provided essential support on how to navigate Covid, and the implications it has on palliative care and still efficiently carry out one’s mandate in CHILDREN’S PALLIATIVE CARE. In Eswatini, the RHP is the only children focused palliative care organisation in the whole country, therefore, one is mindful that the skills and expertise ICPCN shares impacts the whole multidisciplinary team with the child and their family at the center. “Children are our greatest treasure” (Nelson Mandela) and should not be left behind in terms of healthcare. The smallest voices are ones people tend to not pay attention to, therefore it’s our responsibility to lend a listening ear to them and advocate for their needs.

At times webinars can be textbook based and not everyone tends to follow in a productive learning way. The webinars that ICPCN have developed are academically sound, experienced led and practical based. RHP has appreciated the practical case studies that speakers include in their presentations as well as the time that is allocated for questions from the participants. Even after the webinars, one is encouraged to send through questions creating a conducive environment to foster openness and learning.

Alongside these webinars, ICPCN has their E-Learning platform. Many professionals who start working in palliative care are not always fully oriented in the topic. The ICPCN E-Learning are innovative, palliative care focused courses that helps develop knowledge and the necessary skills in palliative care.

RHP and many other organisations, for sure, respect ICPCN and are motivated to make a change in their respective places to advance CHILDREN’S PALLIATIVE CARE with splendid partners alongside us. “Coming together is a beginning; keeping together is progress; working together is success!” (Henry Ford) – resulting in children requiring palliative care receiving it.

Raquel da Silva
Program Manager
The Rocking Horse Project
Our International Board of Trustees

Mike Palfreman
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Our Staff

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.

Prof Julia Downing
Chief Executive

Alex Daniels
Education Manager

Barbara Steel
Admin and Finance Officer

Howard Kinyua
Communications Manager

Funding

We are grateful to all those who have and continue to fund ICPCN. Like other charities the Covid pandemic, along with many of our regular donors closing or stopping funding palliative care, has impacted our funding and we are looking at diversifying and expanding our funding sources. Due to this our annual expenditure decreased greatly but is now beginning to increase as we seek alternative sources of funding. We are also looking at potential fundraising campaigns so that we can expand and develop our work further as we strive to ensure that all children have access to palliative care regardless of where they live in the world.

ICPCN’s annual expenditure 2012 onwards

- Bundesverband Kinderhospiz
- Diana, Princess of Wales Memorial Fund
- DFID
- Edinburgh Medical Missionary Society (EMMS)
- Heb Ffin
- Horizon2020(EU)
- Imperial College
- Isabella Seragnolli Foundation
- Krebs Alliance
- Monument Trust
- Open Society Institute (OSI)
- OSI South Africa
- True Colours Trust
- Oxford GRCF
- St Jude Children’s Research Hospital
- US Cancer Pain Relief Committee
- Wild in Art
- World Child Cancer
- World Health Organisation

Learn More
www.icpcn.org
www.elearnicpcn.org
www.ehospice.com

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ICPCN is a registered charity in England & Wales (number 1143712) and a registered company in England & Wales (number 7675172)

ICPCN is also a registered company in South Africa (number 2011/001648/08) and a registered Public Benefit Organisation (number 930043272)