The ICPCN is administered from within South Africa.

Address: Cluster Box 3050, Assagay, South Africa
Telephone: +27 (0)82 897 4420
Email: info@icpcn.org
Website: www.icpcn.org

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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 (USP)
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 Values and Beliefs
ICPCN is committed to the development of CPC globally. The following values underpin all that we do: passion; empathy and respect for all; empowerment; leadership; innovation; professionalism; integrity; accountability; diversity; evidence-based care and support; collaboration; teamwork; and quality.

ICPCN believes that:
• All children and young people and their families have the right of access to PC;
• PC should begin at diagnosis and continues into bereavement and can be provided wherever the child is;
• That the child and their family are at the centre of the care that we provide;
• The family are the primary caregivers and need to be empowered;
• That collaboration is key to the ongoing development of CPC globally, and children and parents have an essential role in this;
• That CPC is about living life to the full.
About ICPCN

The International Children’s Palliative Care Network (ICPCN) was established in 2005 to raise awareness of the need for children’s palliative care worldwide; to share knowledge, skills and resources; to ensure the voices of children and families were heard; and to advocate for more resources for children’s palliative care. Through this, ICPCN seeks to close the equity gap, so that all children who need palliative care can access it, no matter what country they live in.

The ICPCN is a registered charity and non-profit company in the UK and South Africa. From 2006 – 2011, ICPCN was initially supported by the Hospice and Palliative Care Association of South Africa (HPCA) and was under the Worldwide Hospice and Palliative Care Association (WHPCA) until it became an independent organisation in 2011. ICPCN has an international Board of Trustees with representatives from all regions of the world. Board members are elected for their expertise and ability to represent their country or region.
ICPCN’S ACHIEVEMENTS

Since its inception in 2005 ICPCN has:
- Become the recognised global voice on children’s palliative care.
- Grown its membership to >2,000 individual and >350 organisational members in 125 countries.
- Developed a strong global reputation and a unique role, with a high level of expertise and committed staff.
- Made significant progress towards its previous strategy, representing the voice of children and their families.
- Seen the development of CPC grow globally.

ICPCN’s Estimated levels of CPC Development in 2005

ICPCN’s Estimated levels of CPC Development in 2018
ICPCN’s Achievements include:

**Communication:**
- An essential component of any network.
- Website averages > 3,500 visits every month.
- Monthly newsletter to all members.
- >11,000 Facebook followers, 1,900 Twitter and 200 Instagram followers.
- The International Children’s edition of ehospice has >11,000 readers.
- #HatsOn4CPC events in >25 countries, reaching >1.4 million Twitter impressions.
- An effective communications strategy has been developed and maintained.

**Advocacy:**
- Being the global voice of CPC including global influencing with the WHO and Multilateral Agencies.
- Working with children and their families as advocates for CPC development.
- Working with the WHO as an advisor including being part of the technical advisory group, developing WHO handbooks, training materials etc and is in the process of establishing official relations with WHO.
- Developed links with global organisations such as the UN, UNICEF, CCI, WCC, amongst others.
- Working in collaboration with our members and other PC organisations.

**Research:**
- Developing, implementing and supporting global CPC research e.g. Delphi study on Global PC research priorities, understanding of illness, death and dying, the development of the Children’s Palliative Outcome Scale in Africa (C-POS).
- Undertaking key research to identify the 21.5 million children globally who would benefit from palliative care, with 8 million of those needing specialist PC.
- Has had >250 conference presentations and 65 papers published, including being a co-author on the Lancet Commission Report
- Has held three successful ICPCN conferences in Mumbai, Buenos Aires and Durban.

**Education:**
- 7 e-learning courses in 11 languages with 3,200 individuals accessing from 124 countries.
- Face-to-face training to >1,000 participants from 22 countries.
- Supporting education through supervision of BSc, MSc and PhDs, external examining and providing technical advice.

**Strategic development:**
- The network has contributed to the development of CPC globally.
- ICPCN has provided project support and technical support in a range of countries including: India, Indonesia, Malawi, Swaziland, Lesotho, Rwanda, Uganda, Kenya, Italy, Czech Republic, The Netherlands, Serbia, Ukraine, Georgia, Argentina, and Brazil.
- Development of the ICPCN Pain Assessment App.
- Strengthening of ICPCN itself through the development and ratification of numerous policies and procedures, strengthening financial planning and systems.
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.
STRATEGIC FOCUS

The overall goal is expanded in eight more detailed goals, in five areas of strategic focus, and three areas of organisational focus. The areas of strategic focus are:

Communication
Advocacy
Research
Education
Strategic development

(We use the acronym ICPCN “CARES” to share this message.)

Strategic Focus Area 1: Communications

*Connecting palliative care stakeholders and sharing resources which increase awareness of children’s palliative care worldwide.*

The goal for the plan period is 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.

1. **Updating of communications resources**
   a. Update the current ICPCN resources to create an authoritative, comprehensive suite of information which contains simplified messages, and protocol guidance for the use of these materials.
   b. Carry out ICPCN communications, marketing strategy and brand review.
   c. Establish formal organisational understanding of the ICPCN network of members, ambassadors, people trained, champions, subject matter experts (including education course examiners, media, business etc.), the organisations they represent and their locations, so that the ICPCN network can be briefed on children’s palliative care updates and mobilised to communicate ICPCN information, or otherwise support ICPCN.
2. **Updating digital platforms and materials**  
   a. Update digital platforms so that they are accessible, adaptable, and contain information that stakeholders need and want.

3. **Equipping, empowering and growing network**  
   a. Mobilise key stakeholders (individuals and institutions) to communicate ICPCN messages through their presentations and strategic advocacy events.  
   b. Develop/equip each board member with consistent and compelling wording/messaging so as to have unity of message.  
   c. Board to build connections and trust with global leaders in health, business and other sectors.  
   d. Grow network to include champions, ambassadors and advisors from a range of disciplines, including global business leaders both to provide advice and to promote ICPCN.

4. **Disseminate ICPCN key messages**  
   a. Communicate key messages in a consistent and regular fashion, including communication of ICPCN successes, ICPCN statements on events of global/national interest and targeted communications linked with global and national events to the media and through digital platforms.  
   b. Communicate the impact that ICPCN has on global palliative care services through infographics, films and other media.
The goal for the plan period is 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.

1. Advocacy resource development
   a. UHC package: Develop a children’s palliative care “essential package” of supplies, medication, equipment and services which should be part of UHC for children.
   b. Develop suite of advocacy documents, which are adaptable on a country basis.

2. Advocacy training
   a. Stakeholder/member training: develop training for all ICPCN individuals who use or disseminate the adaptable ICPCN advocacy materials.

3. Advocacy at a global and regional level
   a. Establish formal relations with the WHO.
   b. Increase correspondence with and influence on world leaders.
   c. Promote resources and advocacy messages through strategically-timed international events and conferences, targeted at a widened scope of individuals.
   d. Carry out focused high-impact campaigns.

4. Advocacy at a national level
   a. Increase the voice of parents and children in strategic advocacy messages.
   b. Increase ICPCN strategic advocacy messages at key national events, conferences and policy meetings.
Strategic Focus Area 3: Research

Expanding the evidence-base for children’s palliative care

The goal for the plan period is 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.

1. Drive/Initiate research
   a. Collaborate with research institutions to help frame the children’s palliative care research agenda by identifying key research questions that need to be carried out.

2. Collaborate on research in strategic areas for global children’s palliative care
   a. Collaborate with WHPCA and other global organisations on areas of global importance.

3. Support research
   a. Provide “light-touch” support to members and/or other organisations by sharing resources and connecting people, signposting to Centre for Advanced Palliative Care (CAPC) or other organisations.

4. Disseminate research
   a. Share the growing evidence base with health professionals (including non-palliative professionals who work with children), policy makers and other stakeholders for maximum impact.
Strategic Focus Area 4: Education

*Using education to respond to the global need for children’s palliative care.*

The goal for the plan period is 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.

1. **Identify global training needs and co-ordinate central training repository**
   a. Map existing training available globally.
   b. Develop and promote training information hub.
   c. Identify if existing training meets the global need in terms of: Trainers, Children, Specific areas/ need, Cultural acceptability.

2. **Review and further develop e-learning course in response to need**
   a. Review the current e-learning course and update so that it is more easily navigable, interactive and responsive.

3. **Expand e-learning training available according to demonstrable identified need**
   a. Expand access through development of new course material which meets needs.
   b. Explore possibility of extending to diploma degree course.

4. **Facilitate face-to-face training**
   a. Support regional representatives to carry out training.
   b. Carrying out face-to-face training on a paid project-basis.
Strategic Focus Area 5: Strategic Development

Supporting the development of palliative care services worldwide.

The goal for the plan period is to support 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.

1. **Empower and equip the network to establish palliative care services**
   a. Provide advice in the form of comprehensive resources to any champion seeking to establish a CPC service.
   b. Connect organisations and palliative care champions for mutual learning.

2. **Support development of centres of excellence in strategically identified locations**
   a. Identify strategic locations for development of centres of excellence and key champions (who can drive CPC development) within those countries.
   b. Support the development of centres of excellence for children’s palliative care.
ORGANISATIONAL FOCUS

The five strategic goals are underpinned by goals in three areas of organisational focus, which are the necessary changes in the organisation required for ICPCN to achieve the strategic goals.

Organisational Focus Area 1: Workforce and Governance

The goal for the plan period is 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.

1. Review the staffing structure
   a. Develop and agree staffing structure, skills required and job descriptions.
   b.Restructure staffing according to need.

2. Review the organisational governance structure
   a. Implement an organisational structure to fit organisation need.

3. Strengthen governance
   a. Establish the right size, skills-mix and commitment of board.
   b. Establish and implement clear procedure of accountability from board to CE and vice versa.
   c. Establish a clear system of regular review of existing policies and development of new policies as required.

4. Strengthen organisational management
   a. Effective planning and monitoring put in place.
   b. Establish secure central IT repository for all ICPCN files, and active policy keeping up to date to preserve organisation memory.
   c. Establish new financial systems that will enable improved reporting and monitoring of ICPCN’s finances.

Organisational Focus Area 2: Funding

The goal for the plan period is to increase ICPCN’s revenue resilience ensuring multiple revenue streams and sustainability.

1. Fundraising planning and resource development
   a. Establish fundraising goals.
   b. Develop multi-faceted, regularly updated plan for fundraising.
   c. Develop a suite of resources to present the case for funding global CPC/ICPCN.
   d. Fundraising and networking training.
2. **Building networks to support fundraising**
   a. Build links with global leaders, philanthropists and governments.

3. **Establish multiple revenue streams, in accordance with fundraising plan**
   a. Expand current range of foundations/trusts.
   b. Establish Corporate giving programmes.
   c. Increase income from private donors.

4. **Income generation by charging for activities**
   a. Generate income through ICPCN activities.

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**Organisational Focus Area 3: Collaboration**

The goal for the plan period is to formalise collaborations with global organisations, regional networks, national associations, organisations and health professionals, and parents and children in the delivery of all ICPCN activities.

1. **Collaboration at a global and regional level**
   a. Carry out all global strategic advocacy in collaboration with other global organisations.
   b. Collaborate with global, regional and national organisations on the operational delivery of this plan.
   c. Investigate models of greater responsibility for regional networks to act on behalf of ICPCN.

2. **Collaboration at an organisational and professional level**
   a. Ensure regular communications with all national and regional organisations.
   b. Formalise arrangements for organisations or individuals using ICPCN resources for communications, advocacy, research education or strategic development.
   c. Connect individuals and organisations in the network for mutual learning.

3. **Collaboration with parents and children**
   a. Strategically plan for inclusion of parents and children in key activities
   b. Develop a bank of parents who can be consulted on future projects.
   c. Seek to find out, directly from parents and children, what they really need and want from CPC services.
   d. Engage the voices of parents and children in strategic advocacy and awareness raising.
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The True Colours Trust
The US Cancer Pain Relief Committee

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