The past nine months have been an exciting and challenging time for the ICPCN with the expansion of the staff complement, and increased funding to enable the ICPCN to meet its strategic objectives. As we move towards independent charity registration, we will be strengthened to work as an independent organization with an individual identity. We have been fortunate in receiving excellent support from our funders who not only provide the ICPCN with funds, but also actively ensure that the ICPCN is included in any activities that involve children and help us to build partnerships with other organizations with similar objectives.

The Hospice Palliative Care Association of South Africa has graciously hosted the ICPCN for the past 4 years and at present all our funding, staff appointments and legal registration is through the HPCA. This will change as from 1 October when the the ICPCN in Africa will be legally registered as a Non-Profit company with a Board of Directors.

Staff

The staff complement at present:

**Sue Boucher**, based in Durban works full-time for the ICPCN as the International Information Officer responsible for our information systems, design of materials, networks and website. At times Sue is involved with the Advocacy committee of the HPCA, who pay the ICPCN for her time.

**Barbara Steel**, also based in Durban, is the new and very efficient Administrative Officer, reporting directly to the CEO and Information Officer. Barbara has made a great difference to the administration of our activities. Barbara works 80 hours a month for the ICPCN.

**Dr Julia Downing** is based between the UK and Uganda where she is a visiting professor at Makerere University and is contracted to work part-time 8 days a month as a Consultant and the Education and Research Co-ordinator, leading on an Open society Institute grant to develop an e-learning module that we can use internationally through the ICPCN website. Julia’s other consultancies such as in Serbia, also strengthen the ICPCN. Julia also acts as the secretariat to the Scientific Committee.

**Joan Marston** is the Chief Executive, based in Bloemfontein, and works 80 hours a month for the ICPCN. This also includes project management of the DFID-funded, Help the Hospices led, project.
to advocate for and develop children’s palliative care in Malawi and the Maharashtra Region of India. The other 80 hours are spent project managing the development of children’s palliative care Beacon centres in Tanzania, Uganda and South Africa; overseeing the training and examination of students in all three countries, and advising on advocacy initiatives. This also strengthens ICPCN’s influence in Africa.

**Staff positions to be filled:**

**Finance Officer:** At present the HPCA is paid this part-time salary as they manage the ICPCN funding. From October 2011 a Finance Officer will be appointed in Bloemfontein reporting directly to the CEO and the South African Board. The salary for this position will be provided by funding from the True Colours and Monument Trust.

**Advocacy Officer:** The ICPCN has funding allocated by the True Colours Trust and Monument Trusts to enable the appointment of an Advocacy Officer from November 2011. This position has been advertised and CV’s from a number of suitable candidates are at present being processed.

**Meeting the Strategic Objectives of the ICPCN**

The ICPCN has the following strategic objectives: Advocacy; Education and Research; Information and Networking.

**Advocacy - Responsibility of Joan Marston**

Joan Marston met with Claire Morris the Advocacy lead on the Worldwide Palliative Care Alliance to discuss collaborative advocacy on specific issues regarding children. Claire met with UNICEF in New York and took an information document from the ICPCN. The CEO has met with Ambassador Jimmy Kolker, the HV lead in UNICEF, and his team and this was an opportunity to strengthen ICPCN’s communication with UNICEF. A meeting was held with Kate Tatersall of Help the Hospices to plan the next stage of the DFID project.

Contributions by the CEO have been made to advocacy documents on:

- The role of care and support in HIV and AIDS, as part of a number of alliances including the main collaborative, the Caregivers Action Network (CAN)
- WHO presentation to the World Health Assembly
- A presentation on Maternal and Child Health to UNAIDS and a number of WPCA advocacy documents
- Human rights textbook “Children of the Drug War”

Completion of an assessment of the situation regarding children’s palliative care in Malawi for the Waterloo Coalition and participation in the group involved in planning development in Malawi and Kenya. A coalition meeting was held in Lisbon at the EAPC Palliative Care Congress.
**External organizations:**

The ICPCN has networked with the following organizations:

**PATA** (Paediatric AIDS Treatment Association) which is active in a number of African countries. This organization has requested help with paediatric palliative care assessment tools for a new project they are developing for WHO. A meeting was held with them in Cape Town and they have also asked the ICPCN to be involved in helping PATA organise a paediatric palliative care workshop at their annual meeting in Botswana.

A meeting was held with a representative in Dar es Salaam in June on a visit to the Beacon centre in that city. While INCTR has a palliative care division They need assistance with paediatric palliative care.

**The Elizabeth Glaser Paediatric AIDS Foundation** asked the ICPCN to arrange and present a 5 day Introduction to Paediatric Palliative Care Course in Johannesburg for country representatives from Zambia, Tanzania and Lesotho.

The ICPCN has been providing support to a **Cancer Centre in Khartoum**. There are plans for training at a later stage.

Meetings were held in Geneva with WHO, UNAIDS and Red Cross as well as with the UN Committee on the Rights of the Child and the Human Rights Commission to promote the concept of palliative care for children.

The CEO met with the children’s representative on the **South Africa Human Rights Commission** as well as the **OVC Director for USAID** for advocacy discussions.

We have continued to liaise with Dr Willem Scholten of WHO - Access to Controlled Medicines department and arranged for the Scientific and Advocacy committee to meet with Willem in Lisbon to discuss ways of implementing the guidelines for Persisting Pain in Children.

The CEO is an active member of the Board of the **WPCA** and the **Children's Steering Group of the EAPC**.
**Development of Children’s Palliative Care in Malawi and India**

As a result of the decisions taken by the UK Coalition government regarding DFID funding, our project in India and Malawi will now need to be completed by March 2015 rather than September 2015. The log-frames and budgets have been revised accordingly to complete the project six months earlier than planned. This should not be a problem and both countries should achieve their goals by that time.

In India Dr Raj Bhandari the Country co-ordinator, has completed a base-line survey of the first development site Sion Hospital. Unfortunately we have heard that Dr Raj Bhandari has resigned as country co-ordinator and this will mean a new appointment for the position. Raj has done some excellent ground work and advocacy and we are grateful for his contribution to the project. Development of the first sites has taken place in both countries and new Country Co-ordinators have been appointed as from 1 September.

**Education and Research – responsibility Dr Julia Downing**

In April a meeting was held in London with Prof Blubond-Langner who agreed to become member of the ICPCN Scientific Committee. A meeting of the Scientific Committee meeting was held in July in Lisbon where a number of key decisions were made regarding the way forward.

**Evaluation of the status of PPC education and a TNA**

A survey asking practitioners to indicate what training is available internationally was put live on the ICPCN website for a period of 6 months. A total of 309 people completed this survey from over 50 countries. Information from this survey is in the process of being analysed to inform the ICPCN to where the gaps are in terms of training.

**Web based training curriculum**

Julia and the CEO met with Nic Blackwell from OCB Media and discussed possibilities of future collaboration. He has been sent various information about the training programmes that we have already so that he can see the sort of materials that we have available. We are developing a business plan and budget to source future funding for a large elearning project between ICPCN and OCB media. A pilot elearning module has been developed around the new pain guidelines. This will be piloted in October in four countries. There has been ongoing contact with the DPWMF in terms of their ideas and strategies regarding elearning and the OU.

**Delphi study**

The proposal for the Delphi study was revised according to feedback and has been submitted to the ethics committee in Uganda at Makerere University for approval. We hope to get ethical approval soon.

Julia has continued to work with the editorial team of the International Journal of Palliative Nursing on a themed edition of the journal.
KEHPCA
INTRODUCTION TO PAEDIATRIC PALLIATIVE CARE TRAINING

29TH AUG - 2ND SEPT 2011 AT METHODIST GUEST HOUSE & CONFERENCE CENTRE - NAIROBI
In collaboration with KEHPCA, the ICPCN undertook to train a group of 42 paediatricians, doctors, nurses (and one psychologist) on an “Introductory Course on Paediatric Palliative Care” in Nairobi, Kenya. This course was well received by all and our hope is that it will lead to a greater availability of palliative care services for children in this country.

**Information and Networking – responsibility of Sue Boucher**

In her capacity as the International Information Officer, Sue Boucher continues to undertake the following:

- Immediate response to emails queries and requests for assistance.
- Responding to new members as they join with a letter of welcome, the latest newsletter and a link to the Training and Training needs survey.
- Regular updating of the ICPCN website with information related to children’s palliative care and events on a weekly basis.

**Website statistics**

In the past year September 2010 – September 2011 website statistics are as follows:

- Number of visits: 12,025
- Number of visitors: 8,888
- Number of countries: 149 (The top 10 countries visiting the website being United Kingdom, United States, South Africa, Canada, India, Kenya, Germany, Australia, Uganda and Ireland)

**Partnership project**

Requests for partnerships have been received, mostly from the developing world (Africa) asking for partnerships in the West. A very poor response from Western or even from more developed services in South Africa has been received. These partnership requests have to be vetted carefully as a few do not seem to be from legitimate PPC organizations. Some form of verification of the validity of the organization and its provision of PPC is required. A page for these requests has been created on the ICPCN website.

**ICPCN Membership figures as at September 2011**

- Organisation: 238 from 51 countries
- Individuals: 602 from 62 countries

To date a total of 14 ICPCN eNewsletters (Network News) have been published. These are distributed to the membership and other relevant mailing lists. In March Sue attended a conference in Cork, Ireland, on Early Childhood Development in Developing Countries where she presented on: ‘Lessening the Effects of illness and bereavement through ECD in paediatric palliative care’. At this conference worthwhile contacts were made with influential people in ECD in Cork, South Africa (Bloemfontein) and United States (California). All showed an interest in the possibility of adding a component on PPC in Early Years teacher training.
World Hospice and Palliative Care Day and Voices for Hospice 8 October 2011

The ICPCN team is in the process of editing and working towards the publication of a book of stories, thoughts and poems from life-limited children and from members of their families around the world for publication on World Hospice and Palliative Care Day.

It is envisaged that this publication will be a powerful advocacy tool to be used to persuade decision makers on the need for children’s palliative care and for funding provision.
**Funding and finances**

HPCA continue to manage the finances of the ICPCN. However, as we have grown, we have realized that HPCA no longer has the staff capacity to manage the ICPCN finances and provide regular monthly reports for the executive and finance committee to examine. Once we are a registered charity the ICPCN will be able to appoint their own Finance Officer, open a bank account and manage our finances. At present we have funding committed for three years for the core costs of the ICPCN.

**Challenges**

While we have a steadily increasing membership, and regular requests for advice and training, the present budget does not include sufficient funds for the travel that this involves. Lack of financial reports have made financial management and planning difficult. Without independent registration, advocacy with large international organizations has been difficult and has had to be made through other organizations such as the WPCA.

**Thanks**

The staff would like to thank the Funders, the Executive and our Trustees for their ongoing support and advice.

Joan Marston  
Chief Executive Officer  
September 2011