CONTENTS

Organisational Overview ................................................................. 3
Patch Steering Committee & Staff ......................................................... 4
Chairperson’s Report ........................................................................... 6
Treasurer’s Report ............................................................................. 7
Annual Financial Statement 2018 ......................................................... 8
Advocacy ............................................................................................ 9
Patch Youth Ambassador ................................................................. 10
Hats On for Children’s Palliative Care ................................................. 11
Communication .................................................................................. 13
Education ........................................................................................... 14
Diploma in Palliative Medicine (Paediatric Option) at UCT ............. 15
Conferences ...................................................................................... 16
3rd ICPCN Conference .................................................................... 17
Research .......................................................................................... 19
International Collaborations ............................................................ 19
Acknowledgements ........................................................................... 20
ORGANISATIONAL OVERVIEW

Palliative Treatment for Children (Patch) South Africa is an inclusive and compassionate network that aims to share specialised knowledge, tools and opportunities to ensure the best possible care for children with life-threatening and life-limiting illnesses, and to provide support to families and lay caregivers.

OUR VISION
To ensure the right of every child to access quality palliative care in South Africa

OUR MISSION
To mobilise and support a sustainable network of individuals, organisations, professionals and caregivers to provide holistic and culturally appropriate palliative care for children and their families from diagnosis to bereavement.

OUR OBJECTIVES
Advocacy: To be a strong collaborative voice for the right of children to receive quality palliative care. To influence policy development in children’s palliative care. To advocate for the integration of palliative care into all children’s services.

Information: To be a source of information on children’s palliative care and service providers. To develop and promote locally appropriate guidelines and standards for children’s palliative care.

Education: To provide evidence-based education in children’s palliative care for professionals and caregivers.

Research: To signpost research relevant to children’s palliative care. To drive the research agenda for evidence-based children’s palliative care.

Support: To ensure the voice of the child and family informs all activities of the network. To promote care for the caregiver.

The network consists of 3 different but inter-related networks each represented by a different badge.

Patch SA is constituted as a Voluntary Association of members and is run by a committee with the support of a paid administrator/information officer. This year saw the appointment of Patch’s first Training Coordinator, Tracy Rawlins.

All of the committee members work in the NGO sector and volunteer their time to Patch SA.

PatchSA does not have a physical office- the organisation’s two employees work out of home offices.
PATCH STEERING COMMITTEE & STAFF

Top row from left to right: Sue Boucher, Joan Marston (Vice Chair), Dr Michelle Meiring (Chair), Tracey Brand (Treasurer), Dr Julia Ambler, Fiona McIernan, Dr Jan du Plessis.
Front row: Huyaam Samuels (Youth Ambassador), Melissa Williams-Platt (Family Support), Tracy Rawlins (Training Coordinator), Dr Mehnaaz Ally
Inset: Linda Ganca, Petra Burger

Committee Members

Dr Michelle Meiring
MBchB, M Med (Paeds) FCPaeds
Chair
Dr Meiring coordinates the PG Diploma in Palliative Medicine (Paeds) at UCT; Supervisor MPhil (Palliative Medicine students); CEO of PaedsPal (Paediatric Palliative Care NGO); Next of four editors of the Oxford Textbook of Palliative Care for Children; On WHO PPC Task Team. Dr Meiring has 15 years’ experience in hospice and palliative care and is based in Cape Town.

Mrs Joan Marston
BSoc Sc, MA, RPN
Vice Chair
Joan is a registered nursing sister, Former CEO and Global Ambassador of the International Children’s Palliative Care Network (ICPCN); Founder of Sunflower Children’s Hospice in Bloemfontein, Board member of the Elisabeth Kübler-Ross Foundation, Co Chair of PALCHASE- Palliative Care in Humanitarian Situations and Emergencies. Joan has 29 years’ experience in hospice and palliative care.
Ms Sue Boucher
Dip JP Studies (UKZN); HDE (Pre-Primary) UNISA
Committee Secretary
Sue is an experienced educator and school principal, and early childhood education specialist, a published author of numerous children’s story books and educational Text Books; Director of Communications for ICPCN, Editor of ehospice (International Children’s edition) and has been involved in curriculum development and training in children’s palliative care for HPCA and ICPCN. She has 11 years’ experience in palliative care.

Dr Julia Ambler
MBchB (UCT), MRCGP (UK) Dip Pall. Med.(Cardiff) DCH (CMSA)
Education Portfolio
Dr Ambler is the co-founder and Deputy Director of Umduduzi- Hospice Care for Children in Durban (KZN). She lectures medical students in communication and Paediatric Palliative Care at UKZN and is a lecturer on the UCT Diploma for Palliative Medicine (Paeds) at UCT. Dr Ambler has 15-year experience in Palliative care.

Ms Tracey Brand
MA Social Work
Treasurer
Tracey is the Director of Umduduzi- Hospice Care for Children in Durban (KZN). She has 11 years’ experience in palliative care.

Ms Linda Ganca
BA Social Work, M Phil Palliative Medicine (UCT)
Advocacy Portfolio
Linda is a lecturer in Palliative care at UCT. Based in Cape Town. 16 years’ experience in palliative care.

Mrs Melissa Platt
B Soc Sci, Associate Coaching Course (UCT)
Family Stream Coordinator
Melissa completed the PG Diploma in Palliative Medicine (with distinction) through UCT; Co Founder of Footprints for Sam and the mother of Samuel, who died in 2017. Melissa is based in Johannesburg.

Mrs Petra Burger
BA Social Work; MBA
Representative of HPCA
Petra is the National Disability Mainstreaming Coordinator for the Hospice Palliative Care Association of South Africa. She is based in Johannesburg.

Mrs Fiona McLennan
BA LLB (UCT) PG Dip in Palliative Medicine (UCT)
Dip in Therapeutic Aromatherapy and Therapeutic Reflexology.
Information Officer for PatchSA
Fiona has been working in the field of children’s palliative care since 2013 and has 6 years’ experience in the field. She is based in Cape Town.
Palliative Treatment for Children South Africa (PatchSA) is an inclusive and compassionate network that aims to share specialised knowledge, tools and opportunities to ensure the best possible care for children with life-threatening and life-limiting illnesses, and to provide support to families and lay caregivers.

We are constituted as a Voluntary Association of members and presently run by a committee with the support of a paid administrator/information officer. All of the committee members work in the NGO sector and volunteer their time to Patch SA.

This has been a most successful year for PatchSA mainly due to PatchSA being granted generous funding from the Discovery Fund to allow us to begin the exciting process of developing an holistic and easily accessible training resource on palliative care for children, specific to the South African situation. This funding has also allowed us to employ Mrs Tracy Rawlins as our very first Training Coordinator. Tracy’s work includes overseeing the development of a book on the key elements of children’s palliative care and will feature contributions and expertise from members of our Steering Committee and a dedicated PatchSA Training Team. The book will be published through the popular and well respected Bettercare brand of healthcare books and training programmes. Additional objectives of this funding includes the rolling out of face to face training in children’s palliative care in four provinces, these being:

- Western Cape
- KwaZulu Natal
- Free State
- Gauteng

We look forward to having a quality product that will help us to further our stated objective of not only promoting but also providing access to evidence-based education in children’s palliative care for professionals and parents.

Fundraising for a network continues to be challenging in the current economic climate but we were pleased to raise additional funding to support our work this year through some fundraising events. Our Hatson4CPC awareness raising campaign grew in 2018 with the most successful “Mad Hatter’s Tea Party” event in Cape Town to coincide with the international “Hats On for Children’s Palliative Care” annual event. Additional funding sources have included a few generous donations and membership fees.

This year we were honoured partner with the International Children’s Palliative Care Network (ICPCN), HPCA and Umduduzi - Hospice Care for Children to present the 3rd ICPCN International Children’s Palliative Care Conference held in Durban from 30 May - 2 June 2018. Themed ‘Inspiration, Innovation, Integration,’ the conference fulfilled its promise of providing a platform to learn, share and network for all those working with and caring for children with life-limiting or life-threatening conditions both within South Africa and across the globe. It provided the 200+ delegates a unique opportunity to learn from highly respected local and international experts in the field of children’s palliative care.

PatchSA as the only national network of children’s palliative care experts in South Africa and I believe we have a crucial role to play in advocating for the further development of children’s palliative care services in our country as well as in the training of multidisciplinary teams and team members to improve the lives of thousands of children living with life threatening and life limiting illnesses across the country.

We look forward to making 2019 a year in which our network makes an even greater mark on the paediatric health care landscape of South Africa.

Dr Michelle Meiring
Chair
The Annual Financial Statement printed in this report reflect our audited financial position as at 31 December 2018.

We are very pleased to report that we received a three (3) year grant received from the Discovery Fund, totalling R1 910 183. The first instalment of R600 000 was paid in May 2018.

The Discovery grant funds have primarily been allocated towards the Bettercare self-learning programme material. We have employed a National Nurse training coordinator who has started the much needed training and education in the field of paediatric palliative care in South Africa.

We also raised an additional R77 167.67 in 2018- from Prudential Investments (R20 000), membership fees and a successful fundraising event, Mad Hatters tea party (R35 000). This money has been earmarked to be used to launch the National Children’s task team in collaboration with National government. Our grateful thanks go to Prudential for their donation. We would also like to thank Newmark Hotels for sponsoring the venue and to Autograph Gin for supplying the gin free of charge, as well as to those that donated auction items and prizes for the event.

We continue with our efforts to raise more funding and have recently applied to a programme in the hope to raise funds to develop Paediatric palliative care guidelines for children with cancer in South Africa as well as information booklets for families of children with cancer. We heard on 11 January 2019 that we passed pre-selection and have been invited to submit a full proposal by 11 February 2019. Unfortunately, we were unsuccessful in obtaining this funding.

We have successfully changed our year end to 31 December. The annual audited financials will therefore be for the 10-month period 1 March 2018 to 31 December 2018.

The Annual Financial Statements were issued and signed on 20 March 2019. There were no issues raised by the Auditors. The next audit will be for a full 12-month period.

Aimee Kinsley
Treasurer
# ANNUAL FINANCIAL STATEMENT 2018

**Audited Annual Financial Statement for 10 months ending 31 December 2018**

**Palliative Treatment for Children South Africa (Patch SA)**

Financial Statement for the 10 months ended 31 December 2018

### Statement of Comprehensive Income

<table>
<thead>
<tr>
<th></th>
<th>Figures in Rand: (10 months ended 31 December 2018)</th>
<th>12 months ended 28 February 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donational Income</td>
<td>657 412</td>
<td>35 666</td>
</tr>
<tr>
<td><strong>Operating Expenses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounting Fees</td>
<td>5 950</td>
<td>0</td>
</tr>
<tr>
<td>Bank Charges</td>
<td>2 664</td>
<td>2 919</td>
</tr>
<tr>
<td>Catering Expenses</td>
<td>5 378</td>
<td>0</td>
</tr>
<tr>
<td>Printing and Other</td>
<td>8 052</td>
<td>1 600</td>
</tr>
<tr>
<td>Salaries and Wages</td>
<td>242 102</td>
<td>42 000</td>
</tr>
<tr>
<td>Salaries Company contribution</td>
<td>1 216</td>
<td>0</td>
</tr>
<tr>
<td>Small Assets</td>
<td>4 599</td>
<td>0</td>
</tr>
<tr>
<td>Sundries</td>
<td>0</td>
<td>200</td>
</tr>
<tr>
<td>Travel and Accommodation:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel - Consultants</td>
<td>20 155</td>
<td>0</td>
</tr>
<tr>
<td>Air Travel- Nurse Coordinator</td>
<td>4 045</td>
<td>0</td>
</tr>
<tr>
<td>Accommodation- Consultants</td>
<td>6 125</td>
<td>0</td>
</tr>
<tr>
<td>Road Travel- Nurse Coordinator</td>
<td>1 322</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>300 392</td>
<td>46 719</td>
</tr>
<tr>
<td><strong>(Deficit) surplus for the year</strong></td>
<td>357 020</td>
<td>(11 053)</td>
</tr>
</tbody>
</table>
National Palliative Care Policy Work

Dr Meiring continued to represent Paediatrics on the National Steering Committee for the Palliative Care Policy Framework led by the National Department of Health in 2018.

This year saw the development of an Implementation Plan for the policy. This activity however sadly fizzled out towards the end of the year with no firm commitment from the National Department to start implementing the policy due to a lack of funding. It was also very disappointing not to see the policy that we had all worked so hard on being officially launched.

PatchSA plans to address this apparent lack of commitment from government by holding a high-level stakeholders meeting early in 2019 to engage other children’s health role players and child rights’ activists to ensure the right of all children in SA to receive palliative care is met.
2018 served as a great, constructive and informative year all round for Patch. As youth ambassador, my aim was to create as much awareness and show how imperative palliative care and patient voices are. In order to create awareness not only on a local and national level for South Africa, I partnered with international organisations who harbour the same passion for palliative care such as World Hospice Palliative Care Association (WHPCA), Hospice Association of South Africa (HPCA) and African Palliative Care Association (APCA).

With enormous help from WHPCA and HPCA, I published numerous articles and videos emphasising the importance of patient’s voices and palliative care organisations particularly in low-middle income countries. I was able to represent a patient voice of South Africa at the National Assembly of World Health Organisation by sending video footage and a speech to be read during session by Dr Stephen Connor, Executive Director of WHPCA.

I accepted an offer to help represent palliative care patient voices of South Africa by a three-year partnership with WHPCA, HPCA and APCA for a project called “Patient Power” which aims to raise the demand of palliative care in Ethiopia and South Africa. Being able to partner with these organisations have enabled me to spread the mission and aim of Patch SA effectively.

Lucy Watts (MBE), WHPCA (Claire Morris & Kate Francklin) and I founded a network called Palliative Care Voices in order to elevate the voices of patients with lived experience of palliative care and includes key information about patient involvement in all aspects of their care. Lucy and I participated in key World Day Events by blogging, and using imagery & quotations around all crucial aspects of palliative care.

In order to highlight the importance of pain management within palliative care, I was given the opportunity to be featured in BBC World Service programme: The why factor, pain. The International Children’s Palliative Care Network (ICPCN), developed a brilliant pain app, which I had the honour of testing before it was published.

All of the collaborations and partnerships have been an eye-opener to emphasize how crucial palliative care is. Not only has this been a great opportunity for myself, I have been able incorporate Patch in global advocacy. Personally, this is only the beginning of great things for Patch, allowing us to grow from strength to strength.

Huyaam Samuels
Youth Ambassador
The second Friday in October, which this year fell on Friday 12 October 2018, is a day for raising awareness of the work of children’s hospices and children’s palliative care (CPC) services worldwide. In its 6th year, the annual campaign, known as Hats On for Children’s Palliative Care, uses the hash tag #HatsOn4CPC.

The day aims to raise funds for children’s palliative care, but more importantly, to raise awareness of the rights of very sick children with incurable and life-threatening illnesses to receive palliative care. We know that existing services are mostly in the developed world.

Those of us who live in the developing world are often underfunded and there are inadequate services to meet the overwhelming need. We know that probably as many as a million children or more in South Africa have an illness or a complex medical condition that is appropriate for palliative care. Many of these children have a poor quality of life and suffer from pain and other distressing symptoms which could be controlled and significantly improved with palliative care.

This year, Patch and a number of children’s palliative care services as well as some adult hospices participated in this annual event to raise awareness and funds for children’s hospices and palliative care services in our country.

Events that were held in South Africa on the day included:

- A Mad Hatter’s Tea Party held in Cape Town and organised by Paedspral with funds raised being shared by that organisation and Patch.
- Patch Chair, Dr Michelle Meiring, appeared on a morning TV show to talk about the day.
- A march and an awareness raising programme held at Grey’s Hospital in Pietermaritzburg.
- A number of ‘Wear a hat to school’ days were held around the country with some schools asking children to donate a small amount for a children’s palliative care service.

Mad Hatters Tea Party
This was certainly the highlight of the year for many ladies who had a good excuse to dress up and eat some fancy food all for a good cause. The event was exceptionally well organized and held on World Palliative Care day on the 13th of October at the Ginja Restaurant at the Waterfront in Cape Town.

We were fortunate to have Ryan O’Connor as the MC for the event. A drama company were hired to add to the festive Alice in Wonderland Theme and the food was delicious. We were also entertained by musical items and a lively auction with fabulous prizes added to the occasion. We hope this event will become a regular on the Cape Town Social Calendar.

Patch has found this annual awareness raising day to be a very effective way to make the public more aware of the benefits of palliative care for children and their right to access such care. We look forward to growing the event in 2019.
COMMUNICATION

National Survey of Children’s Palliative Care Services
In 2016 Paedspal completed a survey of children’s palliative care services that has now been published on our website. Through this portal, patients and professionals can find out what palliative care services are available in their area. Services mapped include both clinical services as well as projects providing psycho-social and other child care programmes relevant to chronically ill children. Contact details are provided.

Monthly Newsletters
Our PatchSA administrator Fiona McLennan and graphic designer Sue Boucher produce a monthly newsletter called Patchwork. Fiona is based in Cape Town and also works as an aromatherapist for Paedspal. Sue is based in Durban and is also the Director of Communication for the International Children’s Palliative Care Network.

This newsletter sent to network members who subscribe, provides information on key topics, upcoming events and children’s palliative care services. Each month features a topic often related to a key day in the health calendar and tells the reader about a paediatric palliative care organisation or professional. Topics covered this year included:

- Patient Advocacy
- Aromatherapy in Children’s Palliative Care
- Children and Cancer
- Palliative Care as a Human Right; Edwards Syndrome
- Cockayne Syndrome
- View from a parent: liver transplant
- ICPCN conference and the statistics for the need for palliative care in South Africa
- Complementary therapies in Children’s Palliative Care Life Practitioners
- The work of a Bereavement Doula
- Culture and children’s palliative care
- Father’s perspective on loss; Signs of Depression
- Traumatic Brain Injury
- Self-Care for people working in children’s palliative care

Membership
Membership has started slowly as so many people are being very careful about what they spend. At present we have 23 individual members and one organisational (CANSA).

However, the name of PatchSA is getting out into the public. I have had many queries this year asking for support and assistance, such as advice on hospices and counselling after loss. Even when the query relates to adults, I try to assist, while at the same time explaining that we work with children. PatchSA brochures are distributed at all the events we attend and are clearly reaching people in the communities, hence the phone calls.

We are also involved in the Children’s Cancer Network started by CHOC. I am currently the Vice Chair of the Western Cape branch and there are exciting opportunities for co-operation. Those who work with children who have cancer are not necessarily aware of all that palliative care can do, and at each meeting we give input on our organisations, and this means that palliative care information is being spread through the children’s cancer organisations.

Fiona McLennan
Information Officer
The Discovery project officially commenced on 1 May 2018.

**Proposed activities for 2018/2019**
The following activities were planned:
- Development and design of a Children’s Palliative care Bettercare learning programme.
- Development of 1 day, 3 day and 5-day training courses to be rolled out in year 2 of the project once the Bettercare book has been completed.
- Development of a Children’s Palliative care sensitisation package for roll out from October – see overview of activities below.

**Proposed training targets for 2018:**
- To reach and sensitise 200 multi-professionals to the concept of Children’s Palliative care

**National Team meeting August**
The PatchSA National training team workshop was held over the weekend of 24 -26 August at the Paedsplal offices in Cape Town. The workshop included a recap of the Discovery proposal, presentations on the proposed key competencies and curricula review and allocation of modules to be developed by the various team members.
- On Friday 24th Dave Woods was in attendance and gave a short Power Point presentation on the history and methodologies of the Bettercare learning programme and facilitated a short discussion on suggestions and ideas for the Children’s Palliative Care book to be developed.
- On Saturday breakaway group sessions were held and draft module outlines were developed by the respective members.
- On Sunday feedback was presented to the plenary group by the respective team members and submission dates for drafts of the allocated modules was finalized.

**Sensitisation presentations**
The target for 2018/2019 was to sensitise 200 multi-professionals across 4 provinces to children’s palliative care through either talks/ workshops and / or presentations.

Children’s Palliative Care sensitisation talks and presentations have been facilitated in all four provinces with the total number of 307 attending the presentations and workshops of which 248 were part of the target group of professions for this project. These professionals were made aware of the need to integrate and educate and train all healthcare professionals at an intermediate level in children’s palliative care.

**Development of the Bettercare book/ learning programme**
Unfortunately, due to varying circumstances at the different host sites, the development of the Bettercare book chapters was delayed and a decision was made to relook a new time frame for the completion of the development of the book in 2019.

Tracy Rawlins
*Training Coordinator*
Diploma in Palliative Medicine (Paediatric Option) at UCT

Our chair, Dr Michelle Meiring, convenes the Paediatric elective to the Postgraduate Diploma at UCT together with Red Cross social worker/UCT researcher Dr Rene Albertyn and Durban based Paediatric Palliative Care specialist and Steering Committee member, Dr Julia Ambler.

This is a part time distance-based Diploma that is open to the multi-disciplinary team (not just doctors). Any professional with an undergraduate degree relevant to the field of Palliative Care (Nursing, Social work, Psychology, Paediatrics etc) is eligible to apply. Students attend 2 compulsory contact lecture weeks in January and June and then return in November for a 2-day exam.

The exam includes a communications assessment where students have to role play a communication scenario with a hired actor/actress! The rest of the course is completed on line through UCT’s vula learning platform. Students are required to do 8 assignments and submit a portfolio of learning by the end of the year.

CONFERENCES & SEMINARS

RareX 2018 Conference attendees
Members of the PatchSA Committee presented at a number of local, national and international conferences this year. Conferences provide wonderful opportunities for teaching, sharing ideas and networking.

<table>
<thead>
<tr>
<th>MONTH</th>
<th>CONFERENCES &amp; SEMINARS</th>
<th>PLACE</th>
<th>PRESENTER</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>Week 1 UCT lectures</td>
<td>Cape Town, SA</td>
<td>M Meiring</td>
</tr>
<tr>
<td>February</td>
<td>Vatican Launch of White Paper Conference on the Role of the Church in Palliative Care</td>
<td>Rome, Italy</td>
<td>J Marston</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rome, Italy</td>
<td></td>
</tr>
<tr>
<td>March</td>
<td>Conference of the Belarussian Children’s Hospice</td>
<td>Minsk, Belarus</td>
<td>J Marston</td>
</tr>
<tr>
<td>April</td>
<td>Launch of Lancet Commission Report on Palliative Care</td>
<td>Miami, USA</td>
<td>J Marston</td>
</tr>
<tr>
<td>May</td>
<td>3rd ICPCN Conference on Children’s Palliative Care NNASA- Perinatal Palliative Care</td>
<td>Durban, SA</td>
<td>All Com members</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Durban, SA</td>
<td>J Ambler</td>
</tr>
<tr>
<td>June</td>
<td>3rd ICPCN Conference on Children’s Palliative Care</td>
<td>Durban, SA</td>
<td>All Steering Committee</td>
</tr>
<tr>
<td>September</td>
<td>Withdrawing Life-Sustaining Treatment RareX- Palliative Care in Rare Disease Ethics Seminar (Tygerberg Hospital)</td>
<td>Cape Town,SA</td>
<td>M Meiring</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Johannesburg, SA</td>
<td>J Ambler</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cape Town, SA</td>
<td>M Meiring</td>
</tr>
<tr>
<td>October</td>
<td>Red Cross Pain Workshop Maruzza Foundation Global PPC Conference</td>
<td>Cape Town, SA</td>
<td>M Meiring</td>
</tr>
<tr>
<td></td>
<td>KZN Social Workers Forum</td>
<td>Rome, Italy</td>
<td>M Meiring, J Marston, T Brand, J Ambler</td>
</tr>
<tr>
<td></td>
<td>AbbVIE Neonatal Workshop (Self-care&amp; Burnout)</td>
<td>Durban, SA</td>
<td>J Ambler</td>
</tr>
<tr>
<td>December</td>
<td>Training of Paediatricians in Paediatric Palliative Care Home Based Support for Children with Progressive Brain Tumours</td>
<td>Vietnam, Pretoria, SA</td>
<td>M Meiring, M Meiring</td>
</tr>
</tbody>
</table>
The International Children’s Palliative Care Network (ICPCN)’s 3rd biannual conference came to a successful end on Saturday 2 June 2018. The conference, held in partnership with local organisations Umduduzi Hospice Care for Children, PatchSA (Palliative Treatment for Children in South Africa) and the Hospice Palliative Care Association of South Africa (HPCA) and themed ‘Inspiration, Innovation, Integration,’ magnificently fulfilled its promise of providing a platform to learn, share and network for all those working with and caring for children with life-limiting or life-threatening conditions across the globe.

With delegates representing 43 countries, at the close of the conference one international delegate wrote “Never before have I felt so much at home at a conference. Never before have I been surrounded by so many brilliant, kind, compassionate, unassuming and warm souls all at once. People who refuse to take no for an answer, for whom no wall is too high, no boundary impervious, no child less important than the others. People who insist on looking for the humanity that unites us all.”

The conference began on Wednesday with a full day of pre-conference workshops covering an array of important topics including the effective treatment of pain in children, research in children’s palliative care, ethics in children’s palliative care, children’s palliative care in humanitarian situations and difficult conversations in children’s palliative care.

Workshops were facilitated by respected experts in the field of children’s palliative care including Prof Julia Downing, ICPCN Chief Executive; Dr Sat Jassal, author and editor of the Rainbows Children’s Hospice Symptom Control Manual, co-author of the Oxford Handbook of Paediatric Palliative Medicine and chair and editor of the APPM Master Formulary; Dr Michelle Meiring, founder of Paedspal, a children’s palliative care service in Cape Town, and chair of PatchSA; Dr Richard Hain, editor of the Oxford Handbook of Paediatric Palliative Medicine; Joan Marston, ICPCN Global Ambassador and co-founder of PalChase; Dr Julia Ambler, co-founder of Umduduzi Hospice Care for Children in KwaZulu Natal and Professor Danai Papadatou, Professor of Clinical Psychology at the School of Health Sciences, Dept of Nursing, of the National and Kapodistrian University in Athens, Greece.
The opening plenary session on Thursday included rousing performances by the Open Air School choir and the Djembe Drummer Troupe from Hillcrest Primary School, followed by presentations from Prof. Julia Downing, Chief Executive of the ICPCN; Dr MR Rajagopal, 2018 Nobel Peace Prize Nominee and Founder of Pallium India, as well as Dr Marie-Charlotte Bouesseau from the World Health Organization. KZN Health MEC, Dr Sibongiseni Dhlomo presented on the recently published palliative care policy for South Africa, specifically a commitment to children’s palliative care. He challenged each province with a heavy burden of disease burden to assess where they are in providing palliative care for children.

Conference delegates representing 43 countries, were served a wealth of information from leading experts in children’s palliative care, including presentations on treating pain and managing difficult symptoms in children and young people, perinatal palliative care and transitioning from child to adult services. On the morning of the second day delegates were addressed by Huyaam Samuels, a young adult accessing palliative care services in Cape Town and heard the moving testimony of two Durban families who had been supported by Umduzu Hospice Care for Children through the illness and deaths of their respective children and who continue to be supported by this organisation as they through the bereavement period.

A highlight of the conference was the South African premiere showing of the film, “Hippocratic: 18 Experiments in Gently Shaking the World” produced by Mike Hill and Sue Collins of Moonshine Agency and which featured the ground breaking work of Dr MR Rajagopal, 2018 Nobel Peace Prize Nominee and founder of Pallium India. “That was the most inspiring movie I’ve ever seen!” reported one of the audience members. Dr Rajagopal joined ICPCN’s Chief Executive, Prof Julia Downing, as a keynote speaker during the opening plenary on the first morning.

Two posters were judged the best posters on show for the day for the first and second days of the conference. These were The Need for Sustaining Hope during Communication of Unfavourable News in the Care of Children with Palliative Care Needs: The Experience of Mothers and Health Professionals in Jordan by Maha Atout and Safely Navigating the PICU/NICU A Parents’s Survival Guide: Inspired By Our Brave Son Samuel John Frederick Platt And His Incredible Journey by Melissa Williams Platt.

Sue Boucher
Director of Communications (ICPCN)
Dr Meiring is the course convenor for the Diploma in Palliative Medicine at UCT and Dr Julia Ambler is a lecturer on the course who is also a marker for the assignments. Started in 2009 as an elective to the Adult Palliative Medicine Diploma in the Department of Family Medicine, the degree is now offered as a standalone Paediatric Option in the Department of Paediatrics and Child Health. This was the first year that the Paediatric option was offered by UCT.

Melissa Platt completed the Diploma this year and passed with distinction. She is the first parent to have qualified with this degree.

Three students completed MPhils in Paediatric Palliative Care at UCT this year:

Dr Johannes duPlessis (Bloemfontein, SA): Family experiences and viewpoints of palliative and supportive care for children with cancer: Can we do better?

Dr Cornelius Huwa (Malawi): An investigation of the symptom burden of paediatric cardiology outpatients in Blantyre, Malawi: the patient perspective.

Dr Abidemi Oladoyinbo (London, UK): How well is paediatric pain managed in a private hospital in London? An evaluation of paediatric healthcare provider’s pain management practices.

Although PatchSA is a national South African Network, members of the committee are also engaged in international work. Joan Marston and Sue Boucher are based in Bloemfontein and Durban respectively and work for the International Children’s Palliative Care Network.

Dr Meiring has joined the editorial team for the next edition of the Oxford Textbook of Palliative Care for Children. The main reason for this invitation is to increase the relevance of this sentinel textbook to the global environment and especially developing countries.

Joan Marston is also writing a chapter in this textbook on “Global Paediatric Palliative Care Development”, Melissa Platt is contributing towards a chapter on the parent’s perspective and Sue Boucher is contributing to the chapter on Education and School in Paediatric Palliative Care.

Both Joan Marston and Michelle Meiring sit on a World Health Organisation task team working on a guidance document for policy makers and governments to integrate palliative care in to public health care systems. Joan also serves on the technical advisory committee for WHO.
ACKNOWLEDGEMENTS

Patch is grateful for all the support received over the year and would like to acknowledge the following people for their generous help and support in 2018:

Members of the Steering Committee
Dr Michelle Meiring
Sr Joan Marston
Ms Sue Boucher
Ms Tracey Brand
Dr Julia Ambler
Ms Linda Ganca
Mrs Petra Burger
Mrs Melissa Williams-Platt
Mrs Fiona McLennan

Our Youth Ambassador
Ms Huyaam Samuels

Our Donors
Discovery Fund
Prudential
Newmark Hotels
Autograph Gin

CONTACT US

You can contact PatchSA

By Mail
P. O. Box 434
Rondebosch
7701

By phone
0727323250

By email
info@patchsa.org

Through our website
www.patchsa.org
PatchSA is a registered non-profit organisation
NPO no: 124-201