CONTENTS

Organisational Overview ........................................................................................................ 3

Patch Steering Committee & Staff ..................................................................................... 4

Chairperson’s Report .......................................................................................................... 6

Treasurer’s Report ............................................................................................................... 7

Annual Financial Statement 2018 ....................................................................................... 8

Advocacy ............................................................................................................................. 9

Hats On for Children’s Palliative Care ............................................................................... 12

Communication ................................................................................................................... 14

Education .............................................................................................................................. 15

Conferences ......................................................................................................................... 19

Our Youth Ambassador ....................................................................................................... 20

International Collaborations ............................................................................................... 20

Acknowledgements ............................................................................................................. 21
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.
Committee Members

**Dr Michelle Meiring**
*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**
*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.

**Mrs Aimee Kinsley**
Aimee obtained a Bachelor of Economics degree from Stellenbosch University and spent over 20 years working in the financial services industry, specialising in the retirement fund space. Aimee has worked very closely with Fund trustees and also acted as Deputy Principal Officer for some retirement funds.

**Mrs Melissa Platt**
*Family Stream Coordinator*
Melissa is Sam’s Mum and a bereaved parent. She is also a palliative coach and a professional consultant now strategically focused on the paediatric healthcare sector. Melissa has a Post Graduate Diploma in Palliative, a coaching qualification from the Centre of Coaching at UCT Business School (2015), and a Bachelor of Arts Degree from Rhodes University (1993). She is co-founder of Footprints4Sam.

**Mrs Sue Boucher**
*Committee Secretary & Communications Consultant*
Sue is an experienced educator and school principal, and early childhood education specialist, a published author of children’s story books and educational Text Books. She was the Director of Communications for ICPCN and has been involved in curriculum development and training in children’s palliative care for HPCA and ICPCN. She has 13 years’ experience in palliative care.

**Mrs Lyn Croote**
Lyn is a qualified paramedic. She is the Executive Director of Lambano – a care and Paediatric Medical Step-down Facility/Hospice facility for children with life limiting and life threatening illnesses.
Mrs Busi Nkosi

Busi Nkosi was the Director of Advocacy for the International Children’s Palliative Care Network for 8 years. She is a nurse by profession and spent 20 years working in the South African Department of Health. She is also a Primary Health Care Nurse, Nurse Educator, Nurse Manager and Community Health Nurse.

Dr Jan du Plessis

Dr Jan du Plessis is a paediatric oncologist at the Universitas Academic Hospital in Bloemfontein. He obtained a diploma in palliative care at the University of Cape Town in 2013 and completed and the MPhil in Palliative Medicine degree from the University of Cape Town in 2016. Currently, Dr du Plessis is the acting head of Paediatric Oncology and a lecturer at the University of the Free State for both undergraduate and postgraduate medical students. He has a special interest in paediatric palliative care and haemophilia.

Mrs Zodwa Sithole

Zodwa has worked in the health sector in various disciplines including general nursing, midwifery, community health and palliative care. She holds a B. Cur degree and a master’s degree in Nursing. She managed to advocate for the integration of Palliative Care in the caring of inmates living with life threatening illnesses in the South African prisons; advocated for Palliative Care with Traditional Healers resulting in the development of a Palliative Care curriculum for Traditional Healers. She coordinated the development of Alliance for Access to Palliative Care.

Dr Mehnaaz Akbar Ally

Dr Mehnaaz Akbar Ally is a paediatric palliative care specialist in Gauteng. She heads up the WitsPal Paediatric Palliative Care team at the Chris Hani Baragwanath hospital in Soweto, and Lambano Sanctuary. She is passionate about educating fellow healthcare workers about Paediatric pain and has a special interest in neonatal pain / palliation.

Dr Samantha Govender

Dr Samantha Govender is a Paediatrician based at General Justice Gizenga Mpanza Regional Hospital (previously known as Stanger) in the iLembe Region In KwaZulu Natal. She has a special interest in Paediatric Palliative care. She is passionate about advocating for palliative care for her patients as well as educating health care workers about the benefits of palliative care with the aim of achieving a good quality of life for their patients.

Mrs Tracy Rawlins

Education Manager

Tracy is a professional nurse, midwife and health educator. Her experience in caring for the terminally ill in her community laid the foundation for her qualification in adult palliative care but her heart and passion has always been in working with babies and children. In 2017 she successfully completed her post grad diploma in Paediatric Palliative care medicine, cum laude. Her current role for Patch has afforded her the opportunity to combine both her passion for facilitation and training, and at the same time, assist in caring and supporting children with serious illnesses and families.
Palliative Treatment for Children South Africa (PatchSA) is an inclusive and compassionate network sharing specialised knowledge, information 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 currently constituted as a Voluntary Association of members and presently run by a committee, all of whom work in the NGO sector and volunteer their time to the organisation.

The past reporting year has seen PatchSA make some giant strides in both our advocacy and education efforts and we are hopeful that this progress will mean a greater awareness of not only the ever-growing need for children’s palliative care in South Africa, but also improve access to services.

The High-Level National Stakeholders Meeting held in Braamfontein on 18 March 2019 co-hosted by PatchSA and the Department of Health was undoubtedly a highlight of our year. Amongst others addressing the meeting we heard from veteran health rights campaigner, Mark Heywood, who told the gathering that the Constitution of our country requires the government to implement the South African National Policy on Palliative Care passed in 2017 so children have palliative care as part of basic health services. An outcome of the meeting was the PatchSA 2019 Declaration of Children’s Right to Palliative Care, which we call upon all South Africans to sign.

The annual Hats On for Children’s Palliative Care Day brought in some much needed funding while raising awareness of children’s palliative care around the country. We look forward to even greater participation from schools and businesses in 2020.

The online publication of the Bettercare book, Palliative Care for Children - A guide for improving the quality of life of patients and their families written by the PatchSA Training Team was another momentous achievement for PatchSA and we look forward with great anticipation to seeing the hard copy of the book.

Based on content from the Bettercare book PatchSA facilitated a 5-day face-to-face pilot course on Key Elements of Children’s Palliative Care at Knysna/Sedgefiled Hospice in March. The training was most successful was facilitated and in attendance were 19 healthcare professionals from various organisations and institutions from the Eastern Cape.

Unfortunately Covid-19 and the subsequent lockdown affected our other planned training activities but on the positive side, has also led to opportunities and more efficient ways of working.

As the roll out of face to face training had not been possible due to lockdown, with permission from Discovery, funds that would have gone to training activities were donated to Sunflower, Umduduzi, Footprints for Sam & Paedspal to cover their responses to Covid-19. This also created an unexpected opportunity to create the Patch Academy website, an online learning website we hope to launch later in the year.

We look forward to another year of growth and improving access to palliative care for children in South Africa.

Dr Michelle Meiring
Chair

CHAIRPERSON’S REPORT
TREASURER’S REPORT

The Annual Financial Statement printed in this report reflect our income statement for the audited financial as at 31 December 2019. Current assets holdings as at 31 December 2019 totals R394 044.

We are very pleased to report that we received the second instalment of R600 000, of a three (3) year grant from the Discovery Fund, paid in July 2019.

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

We also raised an additional R30 000 in 2019 though fundraising and donation. A special thank you to Hillcrest Primary school for raising R17 800 on their “Funky Hat Day” and an additional R9 255 raised from the Hats On for Children’s Palliative Care drive.

We continue with our efforts to raise more funding and this is a key focus for the 2020 Financial year.

The Annual Financial Statements were issued and signed on 27 May 2020. There were no issues raised by the Auditors. A sincere thank you to Williams IDM Inc who continue to perform the Patch SA audit on a pro bono basis.

Aimee Kinsley
Treasurer
Financial Statement for the 12 months ended 31 December 2019

**Statement of Comprehensive Income**

<table>
<thead>
<tr>
<th>Figures in Rand: (12 months ended 31 December 2019)</th>
</tr>
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<tbody>
<tr>
<td>Revenue</td>
</tr>
<tr>
<td>Donation Income</td>
</tr>
<tr>
<td>Operating Expenses</td>
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<tr>
<td>Bank Charges</td>
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<tr>
<td>Catering Expenses</td>
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<tr>
<td>Printing and Other</td>
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<tr>
<td>Salaries and Wages</td>
</tr>
<tr>
<td>Consultant and Prof Fees</td>
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<tr>
<td>Advertising and Advocacy</td>
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<tr>
<td>Accommodation</td>
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<tr>
<td>Travel</td>
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<tr>
<td>Finance Costs</td>
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</tbody>
</table>

| (Deficit) surplus for the year                    | 17 268 |

Compiled by Aimee Kinsley

13 August 2020
For children diagnosed with serious life-threatening and life-limiting illness in South Africa, their families are usually shocked to discover there are so few services available to help them cope. In 2014, South Africa was cosponsor of a World Health Assembly Resolution calling on all member states to include palliative care within their health systems, including paediatric palliative care. In 2017, South Africa’s first national policy on palliative care was passed by the National Health Council, but the implementation of the policy has stalled due to a lack of funding.

The Minister of Health appointed a Steering Committee to guide the Department of Health to implement the policy and on 18 March 2019 a subgroup of this Committee called a meeting to consider how to move forward on the stalled policy, particularly for children.

This meeting was co-hosted by PatchSA and the Department of Health and opened by the Chair of the Minister’s Steering Committee, the MEC for Health KZN Dr Dhlomo. The MEC said that little attention had been paid before to children and that we needed to start focusing on children from today. The MEC told of a patient who had died without pain thanks to palliative care. He felt the aim is to make sure that this is not for the few, but for all of us.

The veteran health rights campaigner, Mark Heywood addressed the meeting and pointed out that the current situation is unlawful. The Constitution requires the government to implement the national policy so children have palliative care as part of basic health services. Section 28 of the Constitution aligns with international human rights holding that children’s rights are of paramount importance. Mark explained there is a duty on government to implement the policy immediately to protect children from harm and government may not incrementally implement the policy over time according to available resources. Currently without implementation, children across the country do not receive palliative care. It is estimated that more than one million children are likely to be in need of palliative care although there is little data on the problem.
In addition, many parents living in poverty, give up work to look after seriously ill children. At the meeting the tragic story of a small child was shared, who was terrified to die, knowing that if he did, the Care Dependency Grant, the only income of their family, would stop. At the meeting it was recommended the Department of Social Development extend the Care Dependency Grant by three months into the bereavement period to support grieving parents as they attempt to return to work. It was also heard that children who are temporarily disabled due to treatable malignancies (needing 2 – 3 years of treatment), do not qualify for the Care Dependency Grant despite their serious illness. This grant is only currently available for children who are permanently disabled.

South African Human Rights Commissioner (SAHRC) for Children, Angie Makwetla addressed the meeting and would like to see the next government centralise children’s rights and return the Office on the Rights of the Child to the Presidency. The SAHRC role is to support democracy and hold the state accountable. Angie said there is a lot of work to be done and none of us can achieve it single-handedly. She invited the children’s palliative care community to approach her for assistance.

The meeting heard that the Essential Medicines List used by doctors in public health care facilities to prescribe medicines, does not include suitable medicines for neuropathic pain in children. The meeting recommended that neuropathic pain in children be recognised, and that suitable medicines to address this suffering be included in the list as recommended by expert opinion.

Delegates attending the meeting committed to support a Declaration calling on government to remember the ICPCN Declaration of Cape Town of 2009 and to:

- Take immediate steps to realise the new policy including leveraging funding for paediatric palliative care,
- Establish eight key regional posts in the public sector,
- Distribute the paediatric palliative care guidelines,
- Monitor the ordering of morphine nationally.
Remembering the ICPCN Declaration of Cape Town 2009;

Recognising our country’s ratification of the World Health Assembly Resolution 67.19 May 2014 “Strengthening of palliative care as a component of comprehensive care throughout the life course”,

We commit to working with government and all stakeholders having an interest in the health and welfare of children experiencing severe health related suffering, to implement paediatric/children’s palliative care throughout South Africa within both public and private health care sectors.

Realising that children are not small adults and that the spectrum of diseases including rare diseases affecting them is different, and that they are more vulnerable by virtue of the fact that they are dependent on adult caregivers for care and decision making.

We support the government’s National Policy Framework and Strategy on Palliative Care and call on government to implement this policy which was approved by the National Health Council in April 2017 with special provision for meeting the needs of children and their families.

We recognise that under Section 28 of the Bill of Rights in the Constitution of South Africa, government has a duty to realise children’s right to palliative care as part of basic health care services and as a component of Universal Health Coverage and that International human rights law obligates South Africa to provide generalist integrated and specialised paediatric palliative care services.

We call upon Government to find the budget to implement the policy and allocate resources, since according to Section 237 of the Constitution, government is required to perform its obligations diligently and without delay. The implementation is to include pain relief medicines for children and training on paediatric palliative care.

We call on all relevant stakeholders both governmental and non-governmental to commit to working together to implement palliative care for children throughout all provinces of South Africa.

This declaration includes an Appendix of recommendations arising from discussions at the meeting, structured using the World Health Organisation model for integrating palliative care into the public health system and further proposes for similar integration into private health care for children in South Africa.

Sign the petition here:

https://www.ipetitions.com/petition/Palliative-care-for-every-child-in-South-Africa

Other National Palliative Care Policy Work

Patch was represented by Busi Nkosi on the Alliance for NCD SA through the course of 2019. This group is in the advance stage of developing a national strategy plan with palliative care included in all aspects of the plan.

Busi Nkosi also represented PatchSA on the Patient Huddle – a programme of campaigning for cancer. However, the distance from her home for the meetings was a problem and she hopes that they will take their meetings online.

Covid-19 had significantly curbed PatchSA Advocacy activities in early 2020. PatchSA also had strong media coverage in an article in the Spotlight online magazine which highlighted the important skills that palliative care brings to a pandemic.

The strongest advocacy messages come from the patients and their families so we need to get their voices to the Department of Health.

Busi Nkosi
Advocacy Sub Committee
The second Friday in October, which fell on Friday 11 October 2019, 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 Paedspal.
- Patch Chair, Dr Michelle Meiring, appeared on a morning TV show to talk about the day.
- A march and an awareness raising event held at General Justice Gazinga Regional Hospital in Stanger, KZN.
- 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.

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. In total we raised around R22,000 in funding from these events. We look forward to growing the event in 2020.
#HATSON4CPC 2019 IN PICTURES
Our Enquiries Service
We have received 32 significant enquiries via our website, many asking for assistance for bereaved family members or for support as they have been bereaved. We have also received a number of requests from mothers of very sick children asking for help. Several medical professionals have called upon Patch for palliative care assistance for patients.

Each enquiry has been professionally handled and referred to suitable people or agencies.

Monthly Newsletters
Monthly newsletters have continued to be circulated to 378 people. Mailchimp reports that:
- 40% open them often
- 19% open them sometimes
- 33% open them rarely

Social Media
Our social media following continues to grow. We have:
- Facebook: 1 588 followers
- Twitter: 189 followers
- Instagram: 133 followers
- My grateful thanks to Tarryn Hendricks for her help with Instagram.
- Our most successful (and non boosted) post being one for International Bereaved Mother’s Day in May which reached 39.9K people on Facebook

International Day of the Nurse and Midwife
We held a successful campaign for International Day of the Nurse and Midwife which reached over 10K people. My grateful thanks to all the committee members who donated to the 2 X R500 Checkers vouchers won by 2 lucky nurses in this campaign.

PatchSA Website
The website has undergone a number of changes with added pages and information, including:
- A CPC Formulary
- Information on our published book
- Additional resource pages
- Updated Donation page

Website Stats from April 2018 – March 2019 showed that the PatchSA website had 37,218 visitors who viewed 437,844 pages.

Sue Boucher
Communications Consultant
Monitoring and Evaluation statistics for Discovery
Ongoing sensitisation and training workshops on children’s palliative care were conducted throughout the 4 provinces by the training consultants – a total of 361 health care professionals attended the various workshops and conferences. The target for 2019 was 200 so we overreached that by a considerable number.

Breakdown of healthcare providers is as follows:
- Doctors: 154
- Nurses: 60
- Social Workers: 15
- Clergy: 8
- Allied: 94
- Other: 30

Development of Bettercare book on Palliative Care for Children
There was a slight delay in getting all the chapters/modules submitted by the end of December for the book to be published by end of January but we are happy to say that the book was released online on the 27th March 2020 with the printed version to be launched in June.

Face to Face Training
Between January to February 2020 Sue Boucher and myself developed and designed the power points for each of the modules of the book for the sites to be able to roll out the face to face training workshops and 3-5 day courses.

We were requested to facilitate a pilot of the course by Knysna Hospice and this was arranged for beginning of March. A successful 5-day training course - *Key Elements for Children’s Palliative Care* - was facilitated at the Knysna & Sedgefield Hospice in Knysna with 19 healthcare professionals from various organisations and institutions attending (see narrative report attached for further details on the training).

Here is an extract from our newsletter in March
PatchSA Training Coordinator Tracy Rawlins had this to say,

“This pilot course has been extremely beneficial, not only for the participants, but also for PatchSA. It has helped us to see the inherent value in the modules we offer as well as where we can improve on the implementation of our training.” She added, “we could not have asked for a better group of participants to do the very first PatchSA 5 day course. They were all involved, eager to learn and participate and their contribution towards the final product is invaluable. We are most grateful to each one of them, to Medical Director Dr Janet Stanford, and to Knysna Sedgefield Hospice for giving us this amazing opportunity.”

In March the training team identified the sites/organisation, namely Umduduzi, Paedspal, Sunflower Hospice, Lambano Sanctuary and Footprints for Sam, that would roll out the training of the CPC material. A meeting was held in March and a MOA sent to each site/organisation to sign in order to begin the roll-out. Unfortunately, due to the sudden announcement of lockdown due to COVID 19 the signing and the roll-out of training was placed on hold (and still is on hold until further notice)

Tracy Rawlins
Training Coordinator
Five-day Training held at Kynsna Sedgefield Hospice

Trainers Tracy Rawlins & Sue Boucher with participants at the 5 day workshop in Kynsna
Post Graduate Diploma at UCT
Dr Meiring convenes the Paediatric elective to the Postgraduate Diploma at UCT. 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.
On Friday 13 September, Tracy Rawlins travelled to Gauteng to give a presentation at the Traumatic Incident Response Associations South Africa (TIRA-SA) annual forum.

The topic for the forum for the first day was Grief and Bereavement. Well known Pastor Braam Klopper and grief counsellor presented on “Towards understanding and treatment of bereavement” in the morning and Tracy presented in the afternoon. Her talk had two sessions, the first being Grief, Loss and Bereavement in Children and the second session, ‘Talking to children about their own death or death of a sibling’.

The delegates consisted of a group of pastors, preachers, social workers, trauma counsellors, psychologists, teachers and a play therapist. Tracy reports that feedback received was that the presentations were well received by the group as the need to talk about death and dying in children still largely remains a taboo subject. A question was raised by a junior school teacher on how to assist children in the classroom where there has been a death of a schoolmate and how to talk to children when a child in the class has a life threatening illness and is waiting for a transplant.

Due to time restraints, there was not sufficient time to discuss this in detail but a huge gap was identified – that being the need for teachers to be trained in loss, grief and bereavement. Much interest in our PatchSA organisation was shown and there has been a request to possibly facilitate further grief and bereavement workshops in the near future.

Fittingly, the TIRASA slogan is “creating patches of normality”.

We believe we can work very well together in the future, exploring ways to collaborate.
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.

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<thead>
<tr>
<th>MONTH</th>
<th>CONFERENCES &amp; SEMINARS</th>
<th>PLACE</th>
<th>PRESENTER</th>
</tr>
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<tbody>
<tr>
<td>April</td>
<td>Meiring: Pain and morphine: Myths and Mistakes.</td>
<td>RCWMCH CME Meeting</td>
<td>Dr Michelle Meiring</td>
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<tr>
<td>June</td>
<td>Risky Business Conference Presentation on ‘Resolving Deadlock’</td>
<td>United Kingdom National webinar</td>
<td>Melissa Williams-Platt</td>
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<td></td>
<td>Providing a good death: South African Paediatric Association</td>
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<td>Dr Michelle Meiring</td>
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<tr>
<td>August</td>
<td>Difficult conversations with Children with Brain tumours- Paediatric Brain Tumour workshop</td>
<td>Cape Town</td>
<td>Dr Michelle Meiring</td>
</tr>
<tr>
<td>September</td>
<td>Traumatic Incident Response Association (TIRA) Presentation on Grief, Loss &amp; Bereavement in Children</td>
<td>Jhb, Gauteng Pretoria, Gauteng</td>
<td>Tracy Rawlins Dr Michelle Meiring</td>
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<tr>
<td>October</td>
<td>Non Communicable Disease (NCD) Stakeholder Engagement Meeting 3rd Ukrainian National Conference for Children’s Palliative Care.</td>
<td>WHO Offices, Pretoria Kyiv, Ukraine</td>
<td>Busi Nkosi Joan Marston</td>
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<tr>
<td>November</td>
<td>Adolescents and Transitioning</td>
<td>Groote Schoor Hospital</td>
<td>Dr Michelle Meiring</td>
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<tr>
<td>December</td>
<td>Paediatric Palliative Care as part of Universal Health Coverage. UHC Day workshop.</td>
<td>Cape Town</td>
<td>Dr Michelle Meiring</td>
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<tr>
<td>February</td>
<td>IAPC Kochi- The Essential Role of Nurses in Paediatric Palliative Care</td>
<td>India</td>
<td>Joan Marston</td>
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<tr>
<td>March</td>
<td>Five Day Training on CPC</td>
<td>Knysna, WC</td>
<td>Tracy Rawlins Sue Boucher Melissa Williams-Platt</td>
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<tr>
<td></td>
<td>Risky Business Conference Presentation on ‘The Risk of A Broken Heart’</td>
<td>Red Cross MC Hospital, WC</td>
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OUR YOUTH AMBASSADOR

Huyaam Samuels promoting children’s palliative care on an international radio station

What it means to be an ambassador for PatchSA

As a patient receiving palliative care, I have lived through the struggle of finding help and battling to receive adequate medical care, I would not want to subject anyone to experience that.

Being an ambassador for PatchSA means being able to contribute meaningfully to society and be a part of something greater than oneself. I can be a voice and represent those who need palliative care and create awareness of the dire importance of the field.

As an organisation, PatchSA, works tirelessly to help those children suffering across South Africa from life-threatening and life-limiting conditions, and ensure that practitioners receive adequate training within the field to provide the best possible care.

Representing an organisation of such calibre enables me to live a more fulfilling life filled with purpose and a mission to help others and that for me is the essence of life.

Huyaam Samuels

INTERNATIONAL COLLABORATIONS

Contributions to publications

PatchSA Steering Committee members have been involved in the revised Oxford Textbook of Palliative Care for Children to be published in the first quarter of 2021. Dr Michelle Meiring is an editor alongside Dr Richard Hain, Ann Goldman and Dr Adam Rapaport. Contributions to the book from the PatchSA Steering Committee members include Joan Marston, writing for the chapters on History and Epidemiology and Delivering are Around the World. Melissa Williams-Platt provided information for a chapter on “Lessons from Sam” and the “Samuel Generation of Healthcare” and Sue Boucher led the rewrite of the chapter on Education and school.

Joan Marston, Busi Nkosi and Sue Boucher contributed to chapters for the book Children’s Palliative Care: An International Case-Based Manual edited by Dr Julia Downing, Chief Executive of ICPCN, and published in April 2020.

Dr Michelle Meiring and Joan Marston were on a global team of esteemed experts who collaborated in the development of the International Association for Hospice and Palliative Care (IAHPC) Consensus-based definition of palliative care.

Other publications that Joan Marston has contributed to include:

- EAPC Atlas of Paediatric Palliative Care, including a Journal article on this: Mapping PPC in the WHO-European region. JPSM 60(4)
- A Field Manual of Palliative Care in Humanitarian Crises.
- Neonatal Palliative Care for Nurses. A Mancni.
- Journal article in JPSM. Redefining Palliative Care - a New Consensus-Based Definition.
- Global Development of Paediatric Palliative Care and International Practices for stopping resuscitation measures for children.
- Global Palliative Care series of webinars and Briefing Notes.
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 2019:

Members of the Steering Committee
Dr Michelle Meiring
Sr Joan Marston
Mrs Aimee Kinsley
Ms Sue Boucher
Mrs Melissa Williams-Platt
Dr Jan du Plessis
Mrs Busi Nkosi
Dr Mehnaaz Ally
Dr Samantha Govender
Mrs Zodwa Sithole

Our Youth Ambassador
Ms Huyaam Samuels

Our Donors
Discovery Fund

CONTACT US

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