

Paediatric palliative care network

Tena koutou katoa,

Welcome to our first newsletter from the Paediatric Palliative Care (PPC) Network! This clinical network (CN) was established over 10 years ago, and has recently increased its membership.

With the enthusiasm of Spring and a Fresh Crew, we bring you a newsletter to continue to raise awareness of PPC, spread news, promote education sessions and research in order to communicate what is happening in Aotearoa.



OUR VISION

That pēpē, tamariki, rangitahi and whānau in Aotearoa have access to palliative care that meets their needs.

6 KEY FOCUS POINTS

1. Deliver a Model of Care that is equitable.
2. Ensure integration and coordination of services
3. Promote evidence-based PPC medicine
4. Raise awareness through education.
5. Develop workforce
6. Elevate the voice of the child



PPC EDUCATION FORUM

The education forum is on 3rd Tuesday of the month on Zoom.

Sept - Supporting Children with Cancer who have Palliative Care Needs: CCF, CanTeen and L and B
Oct - Childhood Dementia Initiative
Nov - TBC

Restart Feb 20th, 2024

Ideas for topics welcome, please contact us.

For more information or if you would like to go on our mailing list please contact:

ppcn@paediatrics.org.nz

PPC Education Roadshows

THE PAEDIATRIC PALLIATIVE CARE EDUCATION ROADSHOWS HAVE NOW BEEN HELD IN FOUR CENTRES ACROSS AOTEAROA. OVER 200 CLINICIANS (MEDICAL, NURSING & ALLIED HEALTH) HAVE BEEN ABLE TO ATTEND THIS FREE PROGRAMME AND PARTICIPATE IN A RESEARCH STUDY ENSURING THE EDUCATION PROGRAMME BEST MEET THE NEEDS OF PAEDIATRIC CLINICIANS ACROSS AOTEAROA. WE ARE GRATEFUL TO THE AUCKLAND MEDICAL RESEARCH FOUNDATION FOR GENEROUSLY FUNDING THIS EDUCATION AND RESEARCH.

SESSIONS IN THE PROGRAMME INCLUDE FUNDAMENTALS OF PAEDIATRIC PALLIATIVE CARE (PRINCIPLES, GOALS OF CARE AND ADVANCE CARE PLANNING, COMMUNICATION, SPIRITUALITY, GRIEF & BEREAVEMENT AND SELF-CARE FOR PROFESSIONALS) AND SYMPTOM MANAGEMENT (PAIN, NEUROLOGICAL, GASTROINTESTINAL, RESPIRATORY, EMOTIONAL AND BEHAVIOURAL). THE ROADSHOW ALSO PROVIDES IMPORTANT OPPORTUNITY FOR CONNECTION AND COLLABORATION WITH COLLEAGUES CARING FOR CHILDREN WITH PALLIATIVE CARE NEEDS ACROSS A REGION. THIS PROGRAMME WILL CONTINUE INTO 2024 AND BEYOND.

IF YOU ARE INTERESTED IN HOLDING A ROADSHOW IN YOUR LOCAL REGION – PLEASE CONTACT DR GEMMA ABURN, PRINCIPAL INVESTIGATOR & NURSE SPECIALIST, STARSHIP PALLIATIVE CARE AT GABURN@ADHB.GOV.TZ OR 021 918 152.



TERMINAL LUCIDITY RESEARCH

Natasha Tassell-Matamua is an Associate Professor and Director of the Centre for Indigenous Psychologies in the School of Psychology at Massey University in Aotearoa New Zealand. Along with an international team of experts, she would like to invite you to participate in this important research. The study is exploring terminal lucidity (TL) experiences in children, from the perspective of parents/caregivers and/or clinical personnel who have witnessed TL in children.

It is electronic and should take no longer than 30-40 minutes to complete. All the information and the survey is found here:

www.northampton.onlinesurveys.ac.uk/terminal-lucidity-survey

PLEASE DO FEEL FREE TO FORWARD THIS INFORMATION TO ANYONE ELSE YOU THINK MIGHT BE INTERESTED IN THIS STUDY AND DO FEEL FREE TO CONTACT NATASHA ANY TIME IF YOU WOULD LIKE MORE INFORMATION.

ASSOCIATE PROFESSOR NATASHA TASSELL-MATAMUA
N.A.TASSELL-MATAMUA@MASSEY.AC.NZ

*If you are conducting research and want to be in the newsletter
please contact us on ppcn@paediatric.org.nz*

Websites we recommend

Courageous Parents Network

Full of insightful videos by parents, siblings, and clinicians.

www.courageousparentsnetwork.org

ICPCN

Excellent website full of webinars, e-learning modules and latest international news.

www.icpcn.org

Starship Clinical Guidelines

PPC clinical guidelines for end of life care. Developed by the PPC CN.

www.starship.org.nz

EDUCATIONAL OPPORTUNITIES COMING UP!

Virtual PPC in Oncology Symposium

St Judes Global

Day long symposium with awesome speakers! highly recommend.

If you register they send you the recordings so you don't have to stay up all night!



Pediatric Palliative Oncology Symposium (PPOS)

This year's virtual symposium will focus on the comprehensive care of children with cancer and their

FACE TO FACE CONFERENCE

PPC Westmead Symposium "20 years of SCHN Palliative Care Symposium: What's Next..."

7th - 8th March 2024

Annual - 2 day gathering of PPC clinicians in Sydney, discussing latest PPC research, doing workshops and networking.

Programme yet to be released.

WEBINARS

Childhood Dementia Initiative:

Webinar featuring parents and clinicians discussing their latest report.

<https://events.humanitix.com/childhood-dementia-we-don-t-fit-report>

PPC Research in Conflict Settings:

Emerging research from the Middle East Region.

<https://pallchase.org/wp-content/uploads/2022/10/Webinar-7-Poster-Live-links.pdf>

Please feel free to share other Webinars or Education in PPC with us
ppcn@paediatrics.org.nz