

PPCS NEWS

Issue Autumn 2017

* John Hunter Children's Hospital Paediatric Palliative Care Service

MESSAGE FROM SHAUN

After the wild heat of the summer, and then that rainy March, at last autumn has arrived to slow things down a little; warm blue days with cooler nights give everything a gentler tone.

We hope you all had an enjoyable Easter with family and friends, and that things for your family have been as gentle as possible also.

We also understand that autumn brings some trepidation for families as winter will follow soon with all the possible threats to health it poses. As always we will be around to help with anything you need, or are concerned about.

Finally many of the team are heading on a road trip to Tamworth on the 10th and 11th of May to provide education to health staff and to meet with many of the families we support up there.

So we will see many of you soon, either there or around Newcastle, and speak to the rest of you soon also.

Till then,

Kind Regards from the team.

PPCS TEAM MEMBERS:

- Dr Sharon Ryan, Staff Specialist
4921 3387 or 4921 3000 (after hours)
- Dr Bryony Ross, Staff Specialist
- Dr Shirleen Balbir Singh, Fellow -
0417 355 452
- Amy Wethered, Clinical Nurse
Consultant - 0437 925 219
- Patricia Knight, Clinical Nurse
Consultant - 0408 795 523
- Shaun Wood, Social Worker - 0408
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- Madelon Scully, Occupational
Therapist - 0467 717 810
- Sarah Smith, Bereavement
Coordinator 0437 916 149
- Naomi Pope, Volunteer Coordinator-
4921 3549
- Sue Cronin, Secretary - 4921 3387

13th Annual Paediatric Palliative Care Symposium

By Patricia Knight



A few weeks ago most of the Paediatric Palliative Care Service were fortunate enough to get the opportunity travel to The Children's Hospital Westmead for the 13th Annual Paediatric Palliative Care Symposium.

The symposium was a wonderful day filled with so many learning opportunities. The guest speaker was a prominent Doctor from the Boston Children's Hospital whose lectures around prognosis, the future, and accountability, gave everyone a lot to think about. We then had a fabulous update about the hospice facilities available in NSW, Queensland and Victoria and all the wonderful services they provide.

We heard an excellent lecture on new research in the area of SMA which gave everyone a lot to consider. We learned of the challenges encountered by the very small paediatric palliative care team based in Tasmania. There were also some wonderful qualitative studies being conducted by members of allied health, looking at quality of life in

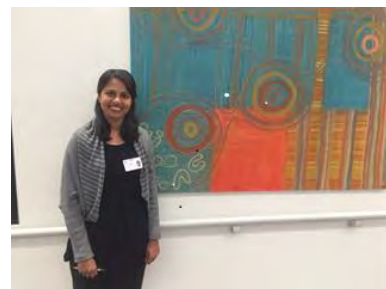
adolescent males in Paediatric Palliative Care Services.

Of course it was also a wonderful opportunity to catch up with our colleagues from other services and hear about all what they have been doing and experiencing.

We left at the end of the day brimming with ideas, and the 3 hr trip home went quickly as we discussed all we had seen and heard.

Our New Fellow

By Shirleen Balbir Singh



It has been wonderful doing the Paediatric Palliative Care Fellow job here in JHCH and the team have been very welcoming.

I was born in Malaysia and did my medical school training at the Royal College of Surgeons in Ireland. After finishing my internship in Ireland, I ventured on a working holiday year in Australia which lead to me continuing my training in Australia and now calling it home.

I am a dual trainee in General Paediatrics and Paediatric Palliative Care Medicine. General Paediatrics has always been my calling and now I feel like I am getting me feet wet in

Paediatric Palliative Care Medicine.

As a trainee in this specialty I am reminded that our duty as healthcare professionals far exceeds curing our sick kiddies and instead extends to the care of those who cannot be treated and families who care for them. To be able to offer care and compassion with dignity to chronic and terminally ill children and their families may be the hardest yet most rewarding part of this specialty.

Outside medicine I love hiking and being outdoors and recently did a half marathon. I am still contemplating if I would attempt another one in the far distant future. I am also definitely a foodie who loves ice-cream and dessaerts. I also enjoy learning and working with a diverse and wonderful group of people. See you soon.

Dealing with Grief

By Sarah Smith



Having been part of the team for almost six months, I have enjoyed getting to know some of our families and being able to provide specialist grief support following the death of a child.

In starting discussions amongst the team about our memorial event to be held later in the year, I am reminded at how challenging special days can be once you have experienced the death of a child. Birthdays, Anniversary's, Christmas', Mother's and Father's Days amongst others can take on a different meaning and feeling

once your child is no longer here to celebrate it with you.

Family traditions may feel strange without your child's participation and the emptiness can feel overwhelming. There is no right or wrong way to acknowledge these days, some families continue to celebrate their child's birthday and for other's they have to create a whole new tradition so that it feels different than before.



You may find yourself becoming more anxious and more distressed as the special day draws closer, especially if you are trying to meet other people's expectations on what you should and shouldn't do. You may find the day is an opportunity for your wider support network to come back together to share stories and memories of your child that may make you laugh and also cry or you may wish to leave town and get away from it all.

Most importantly, you need to be kind and true to your own feelings about what you need at this time. For some people, special days can be the trigger for wanting to access some further grief support, to be able to talk about how they feel, their child and the impact of their grief with someone who is supportive and non-judgemental.

If you find yourself in this position please do contact me on 0437 916 149 or sarah.smith5@hnehealth.nsw.gov.au

Calling for Volunteers

By Madelon Scully



Sharon and Madelon at the Innovation Scholarship Fund presentation.

As mentioned in the last newsletter the service was successful in being granted an Innovation Fund Scholarship for 2017.

We are planning to use technology to link with existing volunteer networks that may operate in regional or rural areas and support and train existing volunteers to become paediatric palliative care volunteers.

We have the first training dates in Port Stephens on May 4th and May 18th.

If you know anyone who is an existing health volunteer who may be interested to be a volunteer for one of our families in Port Stephens, Upper and Lower Hunter or New England areas, please let us know

