Palliative Care Music Therapy

The Palliative Care Service at The Children’s Hospital at Westmead (CHW) is excited to now be able to offer Music Therapy to patients and families who are supported by their service. Roxanne McLeod has recently joined the team and will work alongside the multidisciplinary palliative care staff providing music therapy to children and families while they are in hospital or at home. Roxanne is an experienced Registered Music Therapist who has worked in the CHW Cancer Centre for Children for 7 years. The Palliative Care Music Therapy position has generously been funded by St Johns Bowling Club for 12 months.

Music Therapy in paediatric palliative care can provide many benefits to improve the quality of life for children and their families. Some of these may include:

- Pain management
- Memory making
- Promote participation and function
- Self-expression
- Relaxation
- Sibling/family support.

An initial collaborative project between CHW Music Therapy and Palliative Care Service occurred two years ago with the production of two recorded music CDs. The CDs were created to give families and children opportunities to enhance well-being and family life.

Each CD had specific goals which guided its development. ‘Time for Music’ has recordings of familiar children’s songs that promote function, participation and improved quality of life. The songs are sung by Registered Music Therapists, accompanied by guitar or ukulele. The simple accompaniment was used to replicate the type of music experienced in live music therapy sessions.

‘Quietly’ is a recording of music played on the Reverie Harp. Its aim is to create a sense of calm and tranquility to assist relaxation, rest, breathing, pain and symptom management.

‘Time for Music’ and ‘Quietly’ CDs can be purchased at:


If you would like to know more information about the CHW Palliative Care Music Therapy Program, please contact Roxanne McLeod (Registered Music Therapist) at roxanne.mcleod@health.nsw.gov.au.

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Network Experts Lead the Way in Ground Breaking Research into Spinal Muscular Atrophy

Experts from across Sydney Children’s Hospitals Network were recently part of the ENDEAR study group published in the New England Journal of Medicine, recognised for the significant findings gained in clinical trials in Spinal Muscular Atrophy (SMA) type 1.

SMA is a paediatric disorder which affects the motor neurons of the spinal cord, causing muscle weakness and wasting. SMA causes the premature death of affected children, in the most severe cases before two years of age. There has been no specific treatment for SMA to date. However, results published in the New England Journal of Medicine recently provide new insight into options for families with a child diagnosed with this life-limiting illness.

One study, entitled Nusinersen versus Sham Control in Infantile-Onset Spinal Muscular Atrophy, looked at the safety and efficacy of the Nusinersen treatment. The 15-month study, which enrolled 121 children with SMA type 1 internationally, including children from across Sydney Children’s Hospital, Randwick and The Children’s Hospital at Westmead, was terminated early due to the positive results seen.

The results indicated that those who received Nusinersen were significantly more likely to show improvements in motor function and life expectancy than those in the control group who received a sham medication. The final data showed that 51% reached a motor-milestone response after receiving Nusinersen, with those on the sham treatment at 0%. The likelihood of event-free survival was higher in the Nusinersen group than in the control group as well, with the hazard ratio for death or the use of permanent assisted ventilation at 0.53.

Further research is necessary to confirm the safety and efficacy of this novel therapy, and early detection and treatment need to be explored in regards to Nusinersen. Regardless of the need for this research, this study is significant in the field of SMA and provide hope to families devastated by this rare genetic illness.

“This body of research is an example of what can be achieved for our families through collaboration, with colleagues from across many disciplines across the Network working together to make these ground breaking studies a reality - from research and referrals, through to the continued complex care of these SMA patients. With the General Paediatrics, Intensive Care, Respiratory, Sleep and Neurology teams across Randwick and Westmead involved, it was truly a team effort,” said Dr Michelle Farrar, Staff Specialist and Researcher at Sydney Children’s Hospital, Randwick.

Congratulations go to the research group and Clinical Research Centre staff involved in these studies:

Michelle Farrar, M.D., Nisha Berthon-Jones, Michael Arthur Doumit, P.T., Karen Jane Herbert, P.T., Tejaswi Kandula, M.D., Margot Morrison, R.N., Joanne O'Brien, Stephanie Richardson, R.N., Hugo Alexandre Ferreira Sampaio, M.D., Hooi Ling Teoh, M.D., Catherine (Kate) Hack, Aimee Williams, and Amanda Walkaden.


Closure of HSNet Discipline Specific Groups

In 2010 and 2011 the Children’s Healthcare Network Educators coordinated the creation of the discipline specific networking groups hosted by HSNet. Unfortunately, poor utilisation by allied health professionals has highlighted that these groups do not appear to fulfil the role for which they were created. For this reason the Allied Health Educators have made the decision to close the nine existing groups.

Allied to Kids remains committed to ensuring that opportunities for networking and support of allied health professionals working with children continue to exist. The Allied Health Educators will continue to explore modalities available for the facilitation of virtual communities linked to education and support.
New Education Programs in Paediatric Occupational Therapy

The Clinical Skills Development Service (CSDS) have recently released two new education programs which are free and available on their website at [http://csds.qld.edu.au/sdc/courses](http://csds.qld.edu.au/sdc/courses). The two programs were developed in collaboration with the Simulated Learning in Paediatrics for Allied Health (SLiPAH) team, clinical experts and the Children’s Health Occupational Therapy Department. The programs are aimed at undergraduate occupational therapy students, new graduate occupational therapists and those new to working with infants or burns. The programs are:

**Paediatric Occupational Therapy: Burns (POTB)**

This course aims to improve confidence and skill of participants to enable them to confidently work with infants and children who have disruptions to their occupational performance due to burns. Topics include:

- understanding a paediatric burn
- scar formation
- pre-contact information gathering
- interpretation and assessment
- adherence to and mastery of paediatric burns interventions
- oedema and scar management
- splinting and positioning
- returning to childhood occupations.


**Paediatric Occupational Therapy: Infants (POTI)**

This course provides knowledge around the occupational therapy role and the process for intervention with infants. After completing this course, participants will have insight into the impact of various conditions on occupational performance as well as clinical reasoning in supporting the infant’s best performance. Topics covered include:

- the occupations of infancy
- anticipatory care
- pre-contact information gathering
- assessment and interpretation
- engaging with the baby
- working with the family
- promoting best performance.


Adapted from: [https://csds.qld.edu.au/](https://csds.qld.edu.au/).
Paediatric Rheumatology Network Launches New Website

The Paediatric Rheumatology Network (PRN) was established in 2015 to improve care for children and young people with rheumatologic disorders through the implementation of a best practice model of care. The model of care for the Paediatric Rheumatology Network is published by the Agency for Clinical Innovation.

Recently, the Network launched their website which is a collaboration of organisations that includes The Sydney Children's Hospitals Network, the Agency for Clinical Innovation and Arthritis & Osteoporosis NSW. The website contains information for patients as well as parents and carers including:

- Frequently asked questions such as ‘What's an autoimmune disease?’ and ‘Are rheumatic diseases contagious?’
- Available support agencies
- Information on the different types of arthritis
- How to support children at school.

Further information can be found on the PRN website at http://www.prn.org.au/about/paediatric-rheumatology-network/.


Health Translations

Health Translations enables health practitioners and those working with culturally and linguistically diverse communities to easily find translated health information. The Health Translations Directory provides direct links to reliable translated health resources in Australia.

New resources are regularly added to the database and reviewed to ensure quality and accuracy. It is easy to search for information via topics, languages or organisations.

Clinicians accessing this website or the resources contained within are encouraged to share them with their clients, community, organisation or families.


The Family Matters Report 2017

‘Family Matters - Strong communities. Strong culture. Stronger children.’ is Australia’s national campaign to ensure Aboriginal and Torres Strait Islander children and young people grow up safe and cared for in family, community and culture. Family Matters aims to eliminate the over-representation of Aboriginal and Torres Strait Islander children in OOHC within a generation (2040). Family Matters is led by SNAICC - National Voice for our Children and supported by a Strategic Alliance of over 150 Aboriginal and Torres Strait Islander and non-Indigenous organisations.

Bringing Them Home, the landmark report into the Stolen Generations, was released 20 years ago, in 1997. The Family Matters Report 2017 set out what governments are doing to turn the tide on the over-representation of Aboriginal and Torres Strait Islander children in OOHC, and the outcomes for children and their families. The reports contribute to efforts to change the story by explaining the extent of the problem and reporting on progress towards implementing evidence-informed solutions that aim to eliminate, within a generation, the over-representation of Aboriginal and Torres Strait Islander children living away from their parents and families in statutory OOHC.

The Family Matters Report 2017 Continued

2017 SNAPSHOT DATA

THE ISSUES

ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN
removed by child protection authorities

1997 | 20%
2016 | 36%

9.8 MORE LIKELY TIMES TO BE REMOVED BY CHILD PROTECTION AUTHORITIES THAN NON-INDIGENOUS CHILDREN IN 2016

TRIPLE

2035

IF NO NEW ACTION IS TAKEN
the number of Aboriginal or Torres Strait Islander children removed by child protection authorities will TRIPLE by 2035

THE CAUSES

INVESTING IN FAILURE

In 2015–16, LESS THAN $1 IN EVERY $5 SPENT ON OVERALL CHILD PROTECTION FUNDING was invested in support services for children and their families.

The bulk of spending is in REACTING to PROBLEMS rather than SOLVING them.

POVERTY

LESS THAN $800 MILLION FAMILY SUPPORT FUNDING SERVICES
$4 BILLION CHILD PROTECTION FUNDING SYSTEM

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE ARE 3.5x MORE LIKELY TO BE UNEMPLOYED

1 IN 4 ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE ARE HOMELESSNESS SERVICES IS A CHILD UNDER 10 YEARS

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE ARE 14x MORE LIKELY TO BE HOMELESS

ABORIGINAL AND TORRES STRAIT ISLANDER 5 YEAR OLDS ARE 2.5x MORE LIKELY TO BE HELD BACK IN THEIR DEVELOPMENT
2017 SNAPSHOT DATA

2017 REPORT CARD

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KEY
- Very poor
- Poor
- Promising/improving
- Stronger practice/outcomes

While kinship care, with its strong potential for maintaining cultural, community and family ties, is the best option for ensuring that Aboriginal and Torres Strait Islander children maintain an understanding of their history, connection and identity, it has been consistently decreasing in recent years.

1 IN 2
ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN IN CARE IS PLACED AWAY FROM INDIGENOUS CARERS

2006 | 65%
2016 | 50%

IN THE DECADE SINCE 2006, THE RATE OF CHILDREN PLACED WITH ABORIGINAL OR TORRES STRAIT ISLANDER CARERS HAS FALLEN FROM 65% TO 50%

REUNIFICATION

For children who are removed by child protection authorities, it is important that they have stable, healthy relationships that nurture their identity. We must ensure that children are either placed with or supported to safely return to their families after removal. Increased safe reunification alone could most dramatically reduce over-representation.

Australia does not have any available data on this important issue.
Health Workforce Scholarships Program

The Health Workforce Scholarship Program (HWSP) aims to improve access to health services needed in rural and remote areas by supporting an increase in skills, capacity and/or scope of practice of privately employed health professionals in the fields of medicine, nursing, allied health and Aboriginal health.

The HWSP provides:

- Scholarships to postgraduate health practitioners, undertaking further study in the field of medicine, nursing, allied health and Aboriginal health. Scholarship payments of up to $10,000 per year for up to two years will be available to support participants for full time or part time studies.

- Bursaries to support rural professionals in medicine, nursing, allied health and Aboriginal Health Workers participating in professional development and upskilling courses. One-off bursary payments will be available to cover the cost of training or course fees and/or cover training related expenses such as accommodation and transport.

Eligibility

Health professionals in the fields of medicine, nursing, allied health and Aboriginal Health Workers who provide or will be providing services* to rural and remote locations classified by the Modified Monash Model (MMM) 3 - 7 are eligible to apply.

* if the applicant can demonstrate they will be supplying those services, by providing a service or employment agreement at the time of application.

Scholarships

HWSP scholarships will be available to health professionals undertaking or planning to undertake further study in the field of medicine, nursing, allied health and Aboriginal health that meet the prioritised needs of communities.

Scholarships must directly relate to training and upskilling health professionals who will provide services to rural and remote communities in NSW. Scholarship values will be determined against the perceived workforce benefit of the training for the community. Scholarships of up to $10,000 per year can be provided for up to two years study. Scholarships may be provided for courses that extend beyond 30 June 2020 but study must conclude in the 2020 academic year (by 31 December 2020).

Bursaries

HWSP bursaries are one-off payments that cover the cost of training or course fees and/or cover or partially cover training related expenses such as accommodation and transport, where appropriate. Bursaries must directly relate to training and upskilling health professionals who are or will be providing services to rural and remote communities in NSW. Bursary values will be determined against the perceived workforce benefit of the training.

Scholarships and bursaries are NOT available for:

- Retrospective costs
- Overseas expenses
- Study funded by other sources
- Health professionals employed solely by the relevant State or Territory government i.e. employed in a public hospital
- Activities for which other Federal, State, Territory or Local Government bodies have primary responsibility.

Application Process

Applications open on 20 November 2017 and close on 22 December 2017.

Allied to Kids
Allied health education and clinical support

Further details regarding Allied to Kids is available at the Allied to Kids website: http://www.nchn.org.au/a2k/index.html.

For more details about any of the information included in this newsletter, or if you have something you would like included in a future edition, please contact one of us.

Submissions for Future Editions of Allied to Kids
Let us know about your workshops, new programs, events, research or positions vacant. Clinical articles need to be evidence based with a relevant (albeit short) reference list. Submissions can be sent to any of the Allied Health Educators (email details are listed above) and need to be received no later than the 25th of each month to ensure inclusion in the following month’s edition. Remember, Allied to Kids is a newsletter for allied health professionals by allied health professionals. Please note the inclusion of event/resource details in this newsletter does not constitute endorsement by the NSW Children’s Healthcare Network. Individuals are responsible for determining the credentials of events/resources in line with their own professional standards.

Allied Health Telehealth Virtual Education (AHTVE) 2018 Calendar
The Allied Health Educators are working to develop the 2018 AHTVE calendar. We are seeking your input regarding possible session topics. When suggesting options, please consider:

- Relevance of the topic to allied health professionals who work with children across NSW Health facilities.
- Appropriateness of the topic for a 1 hour AHTVE session (or a series of sessions).
- Possible presenter/s for the topic, either within your department or externally.
- Opportunities to take a multidisciplinary approach to the sessions.

For further details regarding AHTVE, refer to the Allied to Kids website: http://www.nchn.org.au/a2k/telehealth.html.

Should you have suggestions regarding possible topics for the 2018 calendar, please contact your Allied Health Educator (contact details above).
Tertiary Children’s Hospitals Grand Rounds
Available to allied health professionals who provide services through NSW Health

Children’s Hospital at Westmead (CHW) Grand Rounds
The CHW Grand Rounds Education Program has now finished for 2017. Information about the 2018 program will be released in 2018.


John Hunter Children’s Hospital (JHCH) Paediatric Grand Rounds
The JHCH Paediatric Grand Rounds Education Program is held each Tuesday from 1:00 - 2:00pm. Upcoming session topics include (more specific details are released one week prior to the session):

   5 December   Christmas Quiz

For instructions on how to view these sessions online or to access previous sessions, please email Sonia.Hughes@hnehealth.nsw.gov.au.

Sydney Children’s Hospital (SCH) Medical Grand Rounds
The SCH Medical Grand Rounds Education Program is held each Wednesday from 1:00 - 2:00pm.

Upcoming sessions:

   6 December   It takes a village to REHAB a patient   The Rehab Village
   13 December  Doctors vs. Nurses vs. Allied Health:   Dr Avi Lemberg
               The Christmas Quiz

To connect via WebEx go to: https://sesihsmeetings.webex.com/sesihsmeetings/j.php?MTID=m14401bcc57304d7b6500b8a8a46490ce.

Conferences/Workshops/Webinars

Paediatric Dysphagia Interest Group (PDIG)
6 December 2018

Videoconference 3.00 - 4.30 pm
Upcoming PDIG videoconference education session presented by Dr Kelly Weir, Principal Research Fellow Allied Health, Griffith University Gold Coast University Hospital.

To join the Paediatric Dysphagia Interest Group mailing list or for more information contact: Claire Radford, Speech Pathology, Lady Cilento Children’s Hospital, Claire.Radford@health.qld.gov.au.
Conferences/Workshops/Webinars continued

Educating for Collaborative Practice in Healthcare
20 February 2018
Tamworth Education Centre, Tamworth
The University of Newcastle Department of Rural Health (UONDRH) invites you to attend a symposium about current issues and practices in engaging healthcare students and practitioners in teaching and learning for patient-centred collaborative practice. Guest speakers will include Professor Jill Thistlewaite from the University of Technology, Sydney and Dr Margo Brewer from Curtin University. The symposium will be relevant for health professionals, clinical educators or supervisors and university academic staff.
Topics for discussion will include interprofessional practice and education; collaborative practice models for improved patient centred care; and service learning - structured opportunities for student placements with community partners designed to meet academic learning objectives while addressing identified community needs.
Further information may be obtained by contacting Jane Ferns at Jane.Ferns@newcastle.edu.au.

Learning to Conquer the Wees & Poos
9 February 2018
Brisbane, QLD

Lidcombe Program Workshop
26 & 27 February 2018
Perth, WA
19 & 20 March 2018
Melbourne, VIC
https://sydney.onestopsecure.com/onestopweb/VW7/tran?UDS_ACTION=DEFAULT&UDS_ACTION_DATA=1242

Paediatric Fiberoptic Endoscopic Evaluation of Swallowing (FEES) Workshop
2 & 3 March 2018
Brisbane, QLD
Email: LCCH-SPEECH@health.qld.gov.au

TMR Tots and Teens Course - Susan Blum
3 - 5 March 2018
Brisbane, QLD
12 - 14 March 2018
Perth, WA
19 - 21 March 2018
Sydney, NSW

Camperdown Program
22 & 23 March 2018
Perth, WA
https://sydney.onestopsecure.com/onestopweb/VW7/tran?UDS_ACTION_DATA=EiwmADFVxwZOWFV2NkJDA15eQgxMXkUbWkhLkw5PVUJ7NVgg

Mind Brain Education Conference
26 & 27 March 2018
Brisbane, QLD
### Conferences/Workshops/Webinars continued

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<td>The Family Journey from Enteral to Oral Feeding: A Whole Team Approach</td>
<td>11 &amp; 12 June 2018</td>
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The Children’s Healthcare Network Allied Health Educators would like to wish you all a Merry Christmas and a safe and happy new year. Thank you for your participation and ongoing support of Allied to Kids. We look forward to continuing to work with you in 2018.

Best wishes,

*Carmel, Jen, Lisa & Sonia*