

G R A C E

Parents & Carers Newsletter

Edition 2, Summer 2010



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Staff Profile: Helen Mercieca



Name and title/role

Helen Mercieca
Lactation Specialist, Grace Centre for New Born Care & Perioperative Intensive Care Unit

Experience

I have been a registered nurse for just on 19 years. My first three years out of college were spent at

The Nepean Hospital, Penrith, where I gained experience in both medical and surgical areas of adult nursing. After two years, my youthful energy and love of infants soon propelled me into my long desire of becoming a midwife. I spent two wonderful years studying and practicing as a student midwife at Blacktown Hospital. Sadly on completion of my study there was a cut in midwifery positions so work in the area was almost impossible to find so I decided to pursue neonatal care. The challenge of a more intensive neonatal setting inspired me, so in October 1996 I began my career in Grace Centre for Newborn Care. I have now worked in Grace on and off for over 13 years.

Favourite part of the role, least favourite part.

I think it goes without saying that watching an infant who is recovering from major surgery or illness attach to their mother's breast for the first time is definitely rewarding. Even more so when you watch the joy on the mother's/parents' face. It's almost indescribable. It's also really great to get a baby to feed at the breast when feeding has been a struggle. It often takes great patience and commitment from the mother, something I truly admire. The least favourite part of my role as both a nurse and lactation specialist is not being able to offer any hope to a parent, when nothing more medically can be done to assist an infant.

Why I became a neonatal nurse/lactation specialist.

I guess I have been really lucky as from a young age I have always wanted to be a nurse. Spending some time in hospital at the age of ten and having a grandfather with heart disease really prompted this dream. Working with

neonates is enriching as you are experiencing care at the other end of the life spectrum. Babies are new life and there are normally great prospects and a future in front of them once they have recovered. Of course some have a rockier road than others but that makes me even more determined to help.

Often when a baby requires intensive care it is difficult for parents to take an active role in their care because the baby is attached to so much essential and technical equipment. A newborn baby is born with an immature immune system. Assisting a mother to produce milk for her baby which contains many known immunological factors is therefore extremely important. By providing breast milk, the mother is helping her baby's recovery even if she isn't able to give hands on care. So I guess that is the motivation behind my desire to become a lactation specialist in this area. Also struggling with breastfeeding my own children has increased my desire to help other women. I want mothers who have problems like myself to understand that they are not a failure, that some amount of breast milk for their baby is better than none at all.

Aspirations/goals

My goal is to make a positive difference to someone's life in the care I provide, no matter where I am working or what I am doing. If I can't achieve this then the job's not worth doing.

In the short term, my aim is to sit the international exam this July to become a Certified Lactation Consultant.

How do you relax after work?

This question is quite debatable – I have children! No, seriously when all that's necessary is done I love to sit and read to my children, watching their reactions as they become engrossed in the story. I also love fine dining, a nice glass of sauvignon blanc and spending time with my loving husband, family and friends.

What advice do you have for parents in Grace?

I encourage them to ask as many questions as they need to help them come to terms with what is happening with their baby. It is our job as staff to provide as much support and guidance as we can and to make their and their infant's stay as comfortable as possible. The other piece of advice is not to give up, no matter what the prognosis is, your child needs you.

Patient profile: Alana Cheetham

Lisa is a member of the Grace Parent Advisory Council. Lisa and Scott's baby girl Alana was born in 2007 with a heart condition called an aortic coarctation.

“Unbeknown to us, Alana had a serious heart problem... A heart ultrasound revealed that Alana's heart function had deteriorated...”

Our journey at the Grace Centre for Newborn Care began on 31 May, 2007. Two weeks earlier on 15 May, our precious daughter Alana Rose was born at Royal North Shore Hospital (RNSH).



Alana was delivered via emergency caesarean after developing foetal distress. We were overjoyed with the arrival of our first-born child and the first few days went by uneventfully. Unbeknown to us, Alana

had a serious heart problem. The Newborn Screening Test conducted on the day of our intended discharge identified that Alana lacked femoral pulses in her groin area. Subsequent tests by the Paediatricians revealed an Aortic Coarctation (a narrowing of the major vessel leaving the heart). We were advised by our Paediatric Cardiologist that Alana would need surgery to correct the problem, otherwise her tiny heart would tire and fail with its increased workload. The plan was to take Alana home and hopefully wait until she was three to six months old and a little bit stronger prior to the surgery.

On 31 May we attended our second scheduled follow-up appointment at RNSH. We had concerns at this stage that Alana had started to work harder with her breathing and breastfeeding. A heart ultrasound revealed that Alana's heart function had deteriorated and our paediatric cardiologist advised us that it was time to take action. By this he meant we were to proceed straight to The Children's Hospital at Westmead where there would be an intensive care bed waiting for Alana in the Grace Centre for Newborn Care. She was scheduled for surgery the next day!

I cannot adequately describe our roller coaster of thoughts and emotions that afternoon. Although we knew our daughter needed surgery, we never anticipated it would happen quite this soon. We headed straight to The Children's Hospital, anxious about what might lie ahead.

Walking through the doors of the Hospital with your newborn baby is a surreal experience. You always hear so much about The Children's Hospital but you never imagine you will be there two weeks after the birth of your first child. Even at this early stage in Alana's journey, we were quick to acknowledge that there were many families who were worse off than us.

From the moment we arrived, the exceptional standard of care and professionalism of the nursing and medical staff was evident. In addition, the nursing staff ensured that my husband and I had our needs met. They arranged accommodation for us at the Parents Hostel, gave us a Parent Care Pack, which contained some essential items, including toiletries, and told us where we could find a meal. It was the little things like this that made an extremely difficult experience that little bit easier. Meanwhile, numerous doctors attended to Alana in preparation for her operation the next morning.

Dr David Winlaw operated on Alana on Friday 1 June. Walking her through the doors to the operating suites with the nurse was one of the hardest things we have had to do. The next three hours seemed like forever. I will never forget sitting in that waiting room. Finally we were filled with an overwhelming sense of relief when informed that Alana had returned to the Grace Nursery following her successful surgery. Her tiny body was covered with tubes and machines, literally monitoring every breath she took.

“Not only did they do a wonderful job of caring for Alana, they also looked after us”

At this point we thought the worst was over. However, early the following morning Alana's condition acutely deteriorated. Every available resource, in the form of equipment and personnel, surrounded our daughter for the next couple of hours until she stabilised. While this episode was very sudden, it was over as quickly as it had begun thanks to the prompt response of the medical and nursing staff.

Patient profile continued

Alana remained sedated and ventilated for the next three days. During this time she received the very best care from a dedicated team of medical and nursing staff. Not only did they do a wonderful job of caring for Alana, they also looked after us, her parents. Every question we had was answered, every concern we raised was addressed. There was always someone to talk to, always someone to listen and always someone there with the tissues when it all just became too much.

“I had never been so happy to hear a baby cry!”

Four days after her operation, Alana was allowed to wake and come off the ventilator. I had never been so happy to hear a baby cry! Alana made a quick transition to the High Dependency Unit after successfully resuming breastfeeding and being weaned from all medications. Alana and I ‘roomed-in’ together for two nights before finally heading home.

Two and a half years have passed since Alana’s operation. She is now a happy and healthy little girl who continues to thrive in her home environment. We are eternally grateful to everyone at the Grace Centre for Newborn Care who was part of Alana’s journey.



Alana today.

Grace vital statistics

Grace Ward takes its name from Grace Bros Staff Aid to Charities, an organisation which promotes fund-raising for many hospitals. The Children’s Hospital at Westmead has been a major beneficiary since 1924.

Grace is a Neonatal Intensive Care Unit which specialises in caring for babies with surgical, cardiac and complex medical conditions. The neonatal period is defined as the first 28 days of life, but we do care for babies older than that, depending on the condition they have and if they have been born prematurely. We work closely with the PICU and many babies are admitted there if they are outside our criteria.

Over eighty staff are employed on shifts to care for 23 babies at any one time. We are currently funded to have eight ventilator beds and 16 High Dependency beds. Behind the front office there are many back office staff – lactation specialists, occupational therapists and a research team.

Interesting facts about Grace:

- Over 130 babies were admitted in the past three months, and over 620 babies in the past 12 months.
- Average length of stay is approximately eight days.
- There are three shifts for nurses per day - 13 nurses in the morning, 12 nurses in the afternoon and 11 nurses at night.
- The support staff consist of a Nurse Educator and two Clinical Nurse Educators who work rotating shifts to cover the nurses’ needs, two Lactation Specialists that cover six days per week and a Discharge Nurse and Clinical Nurse Consultant who work Monday to Friday.
- Around 840 nappies are used per month!

Tips for parents

- If your stay is extended, do you know you can bring in your own linen and clothes for your baby?
- The outside courtyard is available for use at all times.
- There is a Parent and Carer Resource Centre on level two of the Hospital (opposite Kids Health) which has a microwave, free tea and coffee, couches, a book exchange, internet access and generally provides you a chance to get away for a while.
- Bring in some family photos to show to your baby and help siblings feel a part of the baby's 'home'.
- Colouring books or puzzle books for older children can be a great way to occupy siblings while spending time with their brother or sister.

SIDS Guidelines



1. Sleep baby on the back from birth, not on the tummy or side
2. Sleep baby with face uncovered (no doonas, pillows, lambs wool, bumpers or soft toys)
3. Avoid exposing babies to tobacco smoke before birth and after
4. Provide a safe sleeping environment (safe cot, safe mattress, safe bedding)
5. Sleep baby in their own safe sleeping environment next to the parent's bed for the first six to twelve months of life

www.sidsandkids.org/safe_sleeping.html

Staff in GCNC may not always follow the SIDS Guidelines owing to medical needs of babies. You will be advised if SIDS guidelines are not appropriate for your baby, or speak to a staff member if you're not sure.

Baby advice – Bringing Out the Best in Your Baby

A must for parents and caregivers of children from birth to 12 months of age.

The arrival of a new baby is a very special time, particularly for parents and close family members. This resource has been produced to help support new parents in caring for babies during the first year of life.

Research has shown that the brain develops rapidly in the early years of a child's life. It is important then, that children are stimulated in different ways for healthy development and learning and provided with special care. This begins with holding and comforting your baby, talking and singing to your baby and creating a warm and loving environment for your baby to grow up in. Bringing Out the Best in Your

Baby is a resource that outlines some important activities to encourage your baby's healthy development over the first 12 months, along with developmental milestones so that you may enjoy your baby's new skills.

The resource is given to all new parents in NSW during home visits conducted by Early Childhood Health Nurses. If your child was born in 2009/2010 and you didn't receive a copy, please contact the Early Childhood Health Centre or Community Health Centre in your area. Alternatively, you can download a copy of the resource from the Hospital's website www.chw.edu.au/parents/kidshealth/babys_development/ or visit Kids Health on Level 2 of the Hospital.

Support Group – The Organisation of Congenital Diaphragmatic Hernia Support, Advocacy & Research



CHERUBS Australia is a national support group for families, friends and medical professionals affected by Congenital Diaphragmatic Hernia (CDH). The group consists of families expecting children with CDH, families who have surviving CDH children and families who have lost their babies to CDH. CHERUBS Australia maintains strong ties with the International group.

The Cherubs website contains member's stories and photos, poems, contact information, a quarterly newsletter, information on CDH, links to other relevant sites plus much more. www.cdh.org.au.

What CHERUBS Australia Offers

Listed below are examples of the various forms of support that CHERUBS Australia offer its members:

- Newsletters with group updates, latest CDH news and member profiles.
- Website full of information, links, photos, and stories.
- Group mailing list for members.
- Access to the main CHERUBS member forum.
- Parent-to-parent matching – helping families who have experienced similar CDH situations get in contact with each other.
- Annual member forum held in a different city each year in October.
- Information booklets created for members.
- On-call volunteers available in all states throughout Australia.

Contact CHERUBS

Danielle Kessner - President
Email: information@cdh.org.au
Phone: (03) 5135 6999
Mailing Address: PO Box 375, Morwell, VIC, 3840
Website: www.cdh.org.au

What is a Congenital Diaphragmatic Hernia (CDH)?

Written by
Professor Nadia Badawi,
Consultant Neonatologist

The diaphragm is a muscle that helps us to breathe and separates the chest cavity from the abdominal cavity. It develops in early foetal life. Congenital diaphragmatic hernia is the absence of the diaphragm or, more commonly, the presence of a defect in the diaphragm. It can occur on either the left or the right side but is most common on the left in 80 per cent of cases.

As there is a defect in the diaphragm, the abdominal contents including the stomach, intestine, liver and spleen can be displaced into the chest cavity. CDH is usually an isolated condition, although other congenital anomalies, most commonly cardiac, may be associated and influence the prognosis.

Since these organs are in the chest cavity and not where they are supposed to be, the lungs don't have enough space to grow normally and are therefore smaller than they should be. The determinants of survival include the degree of underdevelopment/ undergrowth of the lung and the supplying blood vessels with associated pulmonary hypertension, as well as the gestation of the baby.

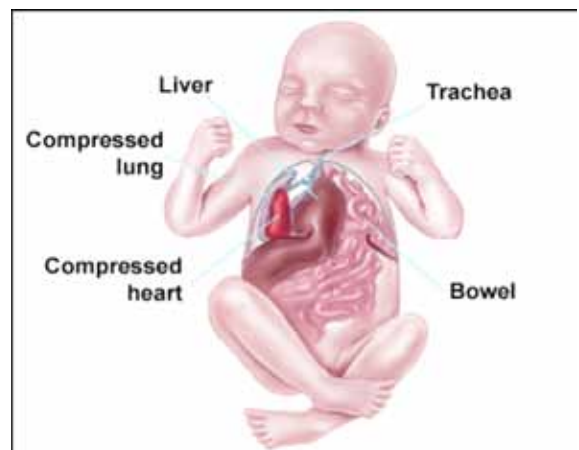


Image Courtesy of The Center for Fetal Diagnosis and Treatment at The Children's Hospital of Philadelphia

Games to play with your baby

Rippling Ribbons

Long before your baby is eagerly tearing paper off packages, ribbons will capture his or her curiosity and attention.

Using sticky tape, attach 15cm lengths of brightly coloured ribbon to a piece of cardboard or tie them securely to a wooden spoon. Gently wave the ribbons around their face and hands. When baby starts to kick their feet and move their arms you'll know they are having fun with the colours, textures and movement.

When their attention wanes or if they fuss and turn their head away, take the ribbons away and play again some other time.

This activity provides eye-hand coordination, tactile stimulation and visual development and a chance for the two of you to interact and bond.

From **Baby Play – 101 fun-filled activities to maximize your baby's potential**. Edited by Dr Wendy S Masi and Dr Roni Cohen Leiderman. Gymboree Play and Music Programs 2001.

We want to hear from you!

We would like to be able to share your stories, experiences and knowledge.

If you have something to say, we are listening. There is a feedback form and secure Suggestion Box located in the Parents Tea room.



Parent Advisory Council

The Grace Centre for Newborn Care Parent Advisory Council (GCNC PAC) was established in 2004 in response to the team at GCNC believing that families are the cornerstone of all activities and processes that occur in the unit.

The PAC is a group of volunteers whose babies were in GCNC and therefore through our own personal experiences, we understand that having a baby in GCNC is a very traumatic time.

Our aim is to make sure there is a place for families to provide their ideas or raise any needs or concerns. The Council also provides a family perspective to GCNC on decisions that need to be made or changes being developed for improving family and newborn care.

We are involved in a range of activities including communication and information for parents, arranging facilities such as the parents library, seeking donations for products for the Parent Care Packs, fundraising for the Centre including Grace's Gala and being available to speak with parents whose babies are in GCNC.

If you would like to be involved we would love to hear from you! You may want to join the Parent Advisory Council or become involved in the Grace Gala.

How can you contact us?

You can either complete a contact sheet and return it in the secure Suggestion Box located in the Parents Tea Room, or you can email us at GCNC@chw.edu.au.

You can obtain more information about Grace Ward and the Parent Advisory Council on our website www.chw.edu.au/parents/fac/grace

Grace Guidelines/Rules

- Always wash your hands every time you re-enter the Centre – this is the most important way to prevent infection.
- Remove watches, coats and jumpers before entering the nursery.
- Store valuables in the lockers provided. Ask the ward clerk for a key.
- No more than two visitors allowed at the bedside at a time.
- No hot drinks in the Centre at any time.

Parent Care Packs

Parent Care Packs are organised by the Parent Advisory Council to provide some essential items to parents who often arrive at Grace with little or no advance warning and no time to prepare and pack. The Parent Care Packs rely almost entirely on donations for the products provided.

We'd like to gratefully acknowledge the support of the following organisations who have supported us: St George Bank, Colgate Palmolive, Nestle, Oral B and Kimberley Clark.

If you have any suggestions of items which would be useful, or you know of any companies who may wish to support us by donating products, please contact us at GCNC@chw.edu.au. Any donation of goods (large or small) is greatly appreciated.

Feature story: Heart Beads



The Heart Beads Program hopes to enrich the experience of cardiac patients and their families at The Children's Hospital at Westmead. Children are rewarded with distinctive beads specific to each procedure or treatment. The children feel a sense of achievement for this courage and the beads help them tell their story.

Who to contact to find out more: Lexi Dengler, Project Officer (02) 9845 1133 or Gabbie Scarfe, Nurse Unit Manager, Edgar Stephens Ward (02) 9845 1143.



Roles and Responsibilities Overview

We know how confusing it can be to understand who is responsible for what within Grace. To help explain, you will find a 'Roles and Responsibilities Overview' on our website at: www.chw.edu.au/parents/fac/grace

Feature story: Grace Gala

**Friday 5 March 2010, 6.30pm,
Art Gallery of NSW.**

The Grace Gala is an opportunity to celebrate and support the life-changing work that is so important to the lives of the babies and families treated everyday at GCNC.

Now in its third year, the Grace Gala has become the Centre's most important fundraising activity. The funds raised at this event continue to provide essential financial support as we strive to provide the best possible care, treatment and follow-up for the hundreds of little babies who come through our doors each year.

We are working hard to not only care for the babies and families when they first arrive at the Centre, but also to provide follow-up care and research so we can monitor the babies as they grow.

As survival rates have climbed significantly over the past ten years in NSW, attention is turning to the quality of outcomes following surgery and, in particular, developmental outcomes. Research shows that major surgery on infants, although necessary and life-saving, may be linked with neuro-developmental impairment. Yet despite the research, these high-risk infants in NSW are not part of any developmental follow-up programmes. Because of this, the opportunity for early intervention maybe missed.

To make sure we can provide the best possible care into the future, we are building a new follow-up clinic and research extension for Grace. This extension will play an integral role in helping the babies we treat to grow up as fit and strong as they can be and will also allow us to undertake essential research into the care and treatment of newborn babies. Early intervention for conditions such as hearing or language problems can make such a difference to a child's life.



The Grace Gala has raised significant funds to date to support the Centre in its follow-up care and research goals. But we need more funds to ensure we can build the centre and provide support into the future.

The 2010 Grace Gala has sold out, with over 300 people attending this wonderful event. A huge thank you to all those who are supporting Grace by attending this event. Your support helps us to pave the way for a better future for the babies who visit the Grace Centre for Newborn Care.

If you would like further information about the event, please contact Melissa French at melissf5@chw.edu.au or phone (02) 9845 3573.

*2010
Grace Gala*

the **children's** hospital at Westmead

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